

**State of Rhode Island  
Department of Human Services**

*Center for Child and Family Health*

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**Certification Standards**

**for**

**CEDARR Family Centers**

**May 25, 2000**

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## I. PROGRAM OVERVIEW

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### 1.1 Introduction

These certification standards are issued for providers of services under the CEDARR Program Initiative. Through this Initiative, the State is defining a set of services for children with special health care needs which it will purchase on behalf of Medicaid eligible children from certified providers. It is intended that through these arrangements the State will ensure timely access to appropriate, high quality services for children with special needs and their families.

The CEDARR Program Initiative is being implemented to pursue a “Statewide Vision for Children and Families with Special Health Care Needs,” developed during 1998-99 by the Leadership Roundtable on Children with Special Health Care Needs, a representative statewide group of family members, providers, public and private administrators, and advocates convened for planning purposes by Christine Ferguson, Director, **Rhode Island** Department of Human Services.

#### *Statewide Vision*

“All Rhode Island children and their families have an evolving, family centered strength based system of care, dedicated to excellence, so they can reach their full potential and thrive in their own communities.”

Leadership Roundtable on Children and Their Families with Special Health Care Needs, April 15, 1999

Through its coverage of services for Medicaid eligible children the CEDARR Program Initiative takes an important step toward achievement of this vision. This initiative will ensure that CEDARR program services are available to all Medicaid eligible children. The CEDARR Program Initiative is intended to enhance services for children with special health needs and their families. It embraces an inclusive view of children and families. Eligibility for CEDARR Family Center Basic Services is not based on any specific definition of “children with special health needs”. In this regard the definition adopted by the Federal Maternal and Child Health Bureau provides guidance:

[Children with special health care needs are] those children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.

Families are eligible to access a CEDARR Family Center at such point as they feel that the services provided may be of value to them. The degree of ongoing involvement will then depend on the individual circumstances and will be voluntary at the family’s discretion.

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The CEDARR Program Initiative further provides a structured system of support for facilitating the assessment of need for, and the provision of, enhanced services that may be available for children and families pursuant to federal Early and Periodic Screening, Diagnosis and Treatment (EPSDT) requirements.

Consistent with the statewide vision noted above, it is anticipated that CEDARR Family Center services will ultimately be available to all children regardless of whether or not they are eligible for Medicaid. It is expected that CEDARR Family Centers will establish sliding scale fee arrangements based on income for families who are not Medicaid eligible.

CEDARR stands for Comprehensive Evaluation, Diagnosis, Assessment, Referral and Reevaluation services and supports. The CEDARR Program Initiative includes two broad delivery system components:

- CEDARR Family Centers, and
- CEDARR Certified Direct Service and Support Providers

This document provides guidance to interested parties who may choose to apply for certification as CEDARR Family Centers.

The services available through the CEDARR Program Initiative will serve to significantly enhance a statewide capacity to implement a broad array of community based, clinically needed , family centered services for children and their families.

This document has been kept as concise as possible. A glossary of terminology, lists of program details, and other explanatory information are contained in appendices.

In an effort to realize this statewide vision for children with special health care needs and their families, the State is issuing these CEDARR Family Center Certification Standards. These certification standards identify the program requirements for participating providers. The State reserves the right to amend these from time to time, with reasonable notice to participants.

## **1.2 Background**

Children with special health care needs and their families often find themselves confronting a system of care which poses significant challenges to even the most prepared. Often, diagnoses are not definitive, treatment options and prognoses are unclear. Families face multiple challenges which must be addressed. There is no single place to turn for assistance. Families frequently encounter a bewildering and frustrating labyrinth of services and eligibility rules pertaining to the different programs. As a result, children are often at-risk for out-of-home placement and encounter barriers to community based service options.

A DHS-sponsored Leadership Roundtable on Children with Special Health Care Needs and their Families, meeting throughout 1999, identified the need for fundamental improvements in the current service system. Rhode Island families of children with special health care needs have important and significantly unmet needs for information, objective professional assessment, care

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planning, care coordination, referral assistance and support. There is a compelling call for a comprehensive array of services which are family centered and community based, recognizing the central role of the family as the constant in a child's life and an essential partner in his/her care.

The Leadership Roundtable emphasized important strengths present in the existing service system (e.g. the CASSP system of care, Early Intervention and LEAs) and critical gains that have been achieved. Emphasis is on affirming current strengths while establishing the means to support new and expanded capacity in critical areas. It is important to ensure that available resources are utilized to full advantage, and that service coordination is maximized, while duplication of effort is minimized.

The CEDARR Family Center is the entity, accountable to both the State and the family, to develop accurate and credible information that identifies effective service and support options currently available in the system, and services and capacities requiring creation, improvement, or expansion. A separate but equal part of the CEDARR Family Center's responsibility is to provide assistance to the family in accessing and coordinating services. These services include the full range of services that impact on children with special health care needs and include but are not limited to health, behavioral health, education, substance abuse and services provided to children involved with the juvenile justice system. The State will assign considerable authority to the CEDARR Family Center, to support this role. The CEDARR Family Center is expected to actively integrate the full range of services into a comprehensive program of care.

Throughout the CEDARR documents the term "health" is intended to be comprehensive in scope and affirmatively includes behavioral health and substance abuse assessments and care.

Services provided through the CEDARR Program Initiative are designed to improve the appropriateness of care, support a more positive family-care system dynamic, promote clinical excellence, improve outcomes and promote overall cost effectiveness. Through the CEDARR model the State furthers its commitment to a high quality standard of care in Rhode Island for children with special health care needs. Over time, it is hoped that payers in addition to State payers realize the value of these services, and recognize them for reimbursement<sup>1</sup>.

### **1.3 Commitment to Family Centered Care**

The CEDARR Program Initiative seeks to incorporate the key elements of family centered, community based care into practice. Participating providers are expected to develop practices

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<sup>1</sup>The statewide vision articulated by the Leadership Roundtable envisions a system of care for all Rhode Island children and their families. As currently constituted, through the CEDARR Program Initiative the State is able to provide direct payment for services provided to Medicaid eligible children. The need for services is much broader than this. Access to CEDARR Family Centers would ideally be available to all children and families in need. Many children who are not eligible for Medicaid at the start may be determined to be eligible at some point in the process. CEDARR Family Centers are expected to provide the Initial Family Assessment on a discounted fee basis to promote access. CEDARR Family Centers and the State will work with commercial insurers to promote payment for services by commercial payers.

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and programs consistent with the principles of family centered care. Core practices of family centered care include:

- Incorporating into policy and practice the recognition that the family is the constant in a child's life, while the service system and support personnel within those systems fluctuate.
- Providing individualized services in accordance with the unique needs and potential of each child and guided by the child and family specific care plan which recognizes health, emotional, social and educational needs.
- Facilitating family/professional collaboration at all levels of hospital, home, and community care:
  - care of an individual child;
  - program development, implementation, evaluation, and evolution; and
  - policy formation.
- Exchanging complete and unbiased information between families and professionals in a supportive manner at all times.
- Incorporating into policy and practice the recognition and honoring of cultural diversity, strengths and individuality within and across all families, including ethnic, racial, spiritual, social, economic, educational, and geographic diversity.
- Ensuring services are provided in the least restrictive, most normative environment that is clinically appropriate.
- Recognizing and respecting different methods of coping present in families and implementing comprehensive policies and programs that provide developmental, educational, emotional, environmental and financial supports to meet the diverse needs of families.
- Encouraging and facilitating family-to-family support and networking.
- Ensuring that hospital, home and community service and support systems for children needing specialized health and developmental care and their families are flexible, accessible, and comprehensive in responding to diverse family-identified needs.
- Appreciating families as families and children as children, recognizing that they possess a wide range of strengths, concerns, emotions, and aspirations beyond their need for specialized health and developmental services and support.
- Ensuring services that enable smooth transitions among service systems and natural supports which are appropriate to developmental stages of the child and family.

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## II. CEDARR PROGRAM INITIATIVE: PRINCIPLES OF DESIGN AND OPERATION

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### 2.1 Flexible System for Purchase of Services: Expanded Services, Provider Certification

As a purchaser of services for Medicaid beneficiaries, the State is prepared to pay for expanded services offered by certified providers. Design of the overall structure of the CEDARR Program Initiative is built on two principles:

- Identifying current service needs and gaps in health care services for children and families with special health care needs.
- Establishing and operating an accountable system for the purchase of appropriate, high quality family centered services to meet those needs.

The State is establishing purchasing mechanisms which make it feasible for high quality, certified providers to provide needed services. DHS is also pro-actively fulfilling its statutory mandate as the State Medicaid agency. Under the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) mandate, all states must screen eligible children, diagnose any conditions found through a screen and then furnish appropriate medically necessary treatment to “correct or ameliorate defects and physical and mental illness and conditions discovered by the screening services.”<sup>2</sup> In doing so, the State must make available all services listed in the federal Medicaid law, “whether or not such services are covered under the state plan.”<sup>3</sup>

All services which have been available to Medicaid beneficiaries in the past will continue to be available. New is the expanded set of services for children with special health care needs paid for through the CEDARR Program Initiative, and specifically the comprehensive CEDARR Family Care Plan described elsewhere in this document. To provide payment for these services, the State has established (a) specific provider types and (b) specific service types. Beginning first with provider types, the State will certify two general classes of provider:

- CEDARR Family Centers
- CEDARR Direct Service and Support Providers

These two classes of provider will play distinct roles.

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<sup>2</sup>42 U.S.C. §1396d(a)

<sup>3</sup> Social Security Act, Section 1905(r)(5)

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### **2.1.1 CEDARR Family Centers**

The CEDARR Family Centers will provide both (a) basic services and supports to families and (b) specialized clinical evaluation and coordination services. At the outset the CEDARR Family Center will work with the child and family to assess current circumstances, continuing needs and reasonable next steps. From here, a CEDARR Family Care Plan will be developed, and continuing Family Care Coordination services may be provided, as appropriate.

The Family Care Plan that is developed will include Direct Service and Support services. The CEDARR Family Center will make referral to all services and supports determined to be necessary for the child and family, and will help to coordinate arrangements for Direct Service and Support. CEDARR Direct Service and Support Provider will also be certified by the State. It is anticipated that in the majority of cases the CEDARR Family Center will continue to work with the family to support efforts to gain access to needed services and to track receipt of services and progress in meeting stated outcomes. Continuing involvement of the CEDARR Family Center is identified here as Family Care Coordination. It is not assumed, however, that in all cases the family will need or desire this continuing involvement with the CEDARR Family Center. The appropriateness of continued involvement with the CEDARR Family Center will depend on the specific circumstances of the child and family.

CEDARR Family Centers will be certified on the basis of their demonstrated ability to provide the required range of basic services and to provide clinical expertise in the following areas:

- Autism spectrum disorders
- Behavioral health
- Technology dependent care
- Severe medical or physical disabilities
- Developmental disabilities

### **2.1.2 CEDARR Direct Service and Support Providers**

CEDARR Direct Service and Support Providers will provide specified Direct Services and Supports intended to fill an identified need in the continuum of available high quality and available services. In some cases, this certification process will help to support a greater level of quality assurance, family engagement, and program consistency than is currently possible under the present EPSDT “Prescription Services” program.

Three areas of CEDARR Direct Service and Support Provider Certification are presently identified:

- Services for Children with Autism Spectrum Disorders
- Community based Behavioral Health Services
- Services to Children Who Are Technology Dependent

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## **2.2 Potential for Future Expansion**

The design of the CEDARR Program Initiative is based on identification of needed services and associated certification of qualified providers. This is a flexible model, permitting modifications and additions as appropriate to need. It may become evident over time that additional areas of clinical expertise and/or Direct Service and Support provision should be added to the CEDARR Program Initiative to more fully address needs.

One of the key responsibilities of the CEDARR Family Center is to identify gaps in the current array of services available to meet children's and families needs, as well as capacity shortfalls. Additionally, the CEDARR Family Center will advise the State as to areas requiring quality improvement and/or corrective action, as well as the criteria upon which direct services and supports should be judged.

## **2.3 Eligibility, Choice, and Scope of Services**

### **2.3.1 Eligibility for CEDARR Program Initiative Services**

CEDARR Program Initiative services are established as EPSDT- based Medicaid services which are eligible for reimbursement by the State for all Medicaid eligible children under the age of 21, including children enrolled in RItE Care.

It is intended that insurance status not constitute a barrier to access for basic CEDARR Family Services. The CEDARR Family Center is expected to establish policies and procedures that facilitate access for the Initial Family Assessment for all children (and families) who present with preliminary indications of special health care need regardless of insurance or Medicaid coverage status. To accomplish this objective, CEDARR Family Centers are encouraged to pursue all available sources of reimbursement or program support. In some cases, as a result of efforts initiated at the CEDARR Family Center, Medicaid eligibility may be determined at a future date retroactive to the initial date of service. For other cases a discounted fee schedule based on income will be established. In other cases, commercial insurers may be prepared to provide reimbursement for some services provided by the CEDARR Family Center.

### **2.3.2 Family Choice in Use of Services**

Each child and family has the choice whether or not to utilize the services of the CEDARR Family Center. In accessing services the child and family can choose any certified CEDARR Family Centers. Based on the strengths and needs of the child and family circumstances and preferences of the family, the expertise of one CEDARR Family Center may be more appropriate for a given child and family than another.

A Family Care Plan developed through a CEDARR Family Center will identify a variety of Direct Service and Support options based on the strengths and needs of the individual child and family. CEDARR Family Centers are to advise families of the full range of providers that offer those services so that families can make their own choices. To assist families to make informed choices, a CEDARR Family Center may also advise as to the relevant strengths of different

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providers pertinent to the circumstances of the child and family. This role as advisor is one of the reasons the State will pay close attention to the separation of the CEDARR Family Center from direct service providers and related arms length agreements.

Families may continue to utilize services currently authorized by Medicaid. Utilization of certified CEDARR Direct Services and Supports, however, will require an association with a CEDARR Family Center.

In some instances a family may choose not to associate with a CEDARR Family Center and establish a relationship with a direct service provider on its own. If such a family then seeks to access a CEDARR Family Center for some of the CEDARR support services, the CEDARR Family Center will perform an Initial Family Assessment and provide support services as appropriate. This assessment will include review of current diagnostic and treatment information as part of its effort to understand family circumstances. The CEDARR Family Center is to take all appropriate steps to avoid unnecessary duplication of plans, coordination efforts and services.

### **2.3.3 Scope of Covered Services and Family Care Plan**

A Family Care Plan may include Medicaid services that are newly covered as part of the CEDARR Program Initiative and which are provided by CEDARR certified Direct Service and Support Providers. To the degree that these are included in the Family Care Plan they will be treated as Medicaid covered services. Medicaid covered services, including services otherwise referred to as “EPSDT prescription services”, which are included in the CEDARR Family Care plan are deemed to be authorized services. Prior to CEDARR the only way to access EPSDT prescription services was through submission of proposed treatment plan to DHS for approval. This is no longer necessary for services contained within the CEDARR Family Care Plan.

The Family Care Plan is not limited to Medicaid covered services. It may identify services related to a need which are provided or paid for by another State or local public agency; it may identify services/activities which are seen to be of value but for which no payer is available. The Family Care Plan is intended to be comprehensive and holistic in the interests of the family and not to conform to the funding or service constraints of existing programs; it is to be built upon the strengths and needs of the child and family.

Identification in a Family Care Plan of services that may be available through another public agency does not in any way bind that public agency. However, to the degree feasible in the specific circumstances and available time frame the CEDARR Family Center is required to coordinate its efforts with other parties. If a Family Care Plan is developed in collaboration with other parties (e.g. LEAs, Early Intervention, DCYF and its system of services such as CASSP) the Family Care Plan will identify services which the other agency has agreed to finance.

### **2.4 Sign Off on Family Care Plan by Parent or Other Appropriate Individual**

The CEDARR Program Initiative places strong emphasis on family involvement. It is required that the child’s parent(s) or guardian actively participate in the development of and sign-off on

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the CEDARR Family Care Plan and on any plan for CEDARR certified Direct Service and Support Services.

The State recognizes that children live in widely varied family circumstances. The intent of the parent sign off requirement on care plans is that the adult(s) most involved in promoting the child's welfare fulfill this role (including a grandparent or other responsible family member). In the case of divorce it would be the custodial parent.

In cases where the child has been placed in the protective custody of DCYF, DCYF should identify who should play this role on behalf of the child(e.g. case worker, foster parent).

It is the CEDARR Family Center's responsibility to identify and involve the legally responsible adult. Collaborating agencies, such as the LEA or DCYF can be of assistance. In the case of dispute as to the legal standing of a parent or agent, the CEDARR Family Center shall ask the advice of the State.

## **2.5 Coordination With Other Parties**

It is a fundamental objective that the CEDARR Program Initiative act to help integrate services and systems that often feel fragmented and disjointed for families. The CEDARR Family Center must demonstrate integrated relationships with existing community resources (specifically including LCCs, Early Intervention and LEAs). The CEDARR Family Center will play the principal role as organizer, information source, guide, advocate, facilitator. It will help to assess strengths and needs, identify treatment goals and services, and navigate agency and system boundaries. This means active coordination with other entities in support of the interests of the child and family. It includes recognition that the issues at hand can be genuinely difficult. A valuable service for families can be development of an integrated Family Care Plan that includes identification of the services and supports provided through other means and agreement as to which entity is responsible for the delivery and payment for various needed services. Identification and use of natural supports is also encouraged. In many cases development of these types of joint agreements would be a significant step forward.

The CEDARR Family Center is expected to actively coordinate its efforts with other involved and responsible parties. To the extent that joint and collaborative family centered planning can be carried forward on a timely basis such collaboration should prevail. There may, however, be a variety of factors in such discussions that could, if permitted, delay timely implementation of medically necessary services for the child and family. In such case the primary obligation of the CEDARR Family Center is to meet the needs of the child and family as fully as possible within the existing limits. In such a case an initial Family Care Plan, in addition to providing for immediate services, may include Family Care Coordination services which continue to work toward an integrated plan for the family and at that point an appropriately amended Family Care Plan. Some potential areas where active coordination may be required are noted below.

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### **2.5.1 Other State and Local Public Agencies**

There are a range of State and local agencies which may be actively involved with a child with special health care needs. These include (but are not limited to) Local Educational Authorities (LEAs), DCYF supported LCCs, and Early Intervention. Each of these agencies functions with a set of legal obligations and authorities, funding arrangements and limitations, and service capabilities. A long-standing and widely shared goal has been the development of a system which blends these several resources in as seamless and productive a manner as possible for the family. It is expected that the CEDARR Family Center staff will work closely with representatives from other agencies to identify opportunities for unified plans. In the case of children within the custody of DCYF, the requirement that the parent sign off will ensure direct involvement of the DCYF caseworker or designated agent. In this way an integrated Family Care Plan will be achieved. This Family Care Plan shall consider appropriate services provided through, and linkages with, DCYF supported programs (e.g. CASSP, CIS).

With respect to Special Education and Early Intervention, there may be considerable overlap between the services and needs identified in an IEP or IFSP and those in the CEDARR Family Care Plan. There should be an emphasis on coordination with the IEP or IFSP. There may be instances where a fully articulated Family Care Plan could include family and LEA acceptance of the Family Care Plan as all or part of the IEP. A jointly signed care plan should be pursued which identifies the source of payment (or lack thereof) for included services.

### **2.5.2 Existing Systems of Care**

In addition to and often in conjunction with the various public agencies involved with children with special health care needs, there are existing providers and systems of care providing services to these children and their families. The State anticipates that these existing providers and systems of care will provide many of the services to which CEDARR Family Centers will refer, and that the CEDARR Program Initiative will provide new avenues with which to explore and assess creative solutions to the challenges faced by families of children with special health care needs, as well as the improvements in overall system performance that will satisfy them. A central goal is to provide children and their families' access to services through a seamless system. The CEDARR Family Center shall emphasize linkages with community interagency structures from major child and family service agencies, including at a minimum health care, education, child welfare, juvenile justice and other community natural supports and family representatives.

The CEDARR Program Initiative identifies a series of expectations and performance requirements for providers. Based on these standards, the State will pay for approved and certified services. The State encourages existing providers to propose creative approaches to meeting these standards, perhaps drawing on the unique strengths of partnering entities to enable combined system improvements.

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### **2.5.3 Primary Care Provider**

In most instances the child will have a primary care provider (PCP). It may have been the PCP who referred the child and family to the CEDARR Family Center. If the child does not have a PCP, the CEDARR Family Care Plan should include identification of, and assistance in linking with, a PCP. It is anticipated that the PCP will be an active partner with the child and family and the CEDARR Family Center should work closely to coordinate efforts with the PCP.

### **2.5.4 RItE Care Plans, Other Third Party Payers**

The CEDARR Family Center will be required to coordinate its efforts with a variety of payers. The insurance coverage status of children using the CEDARR Program Initiative will vary. The State agrees to pay for certified Medicaid services to Medicaid-eligible children either directly on a fee for service basis or through RItE Care contracted health plans. For children covered through RItE Care certain services will be “in plan” and the responsibility of the health plan; other services are “out of plan” and will be paid directly on a fee for service basis by the State.

The CEDARR Family Center is expected to be fully knowledgeable concerning the programmatic elements and eligibility rules of all publicly financed programs, and the requirements of all commercial payers’ products and programs to enable it to support the family’s need for information, and for it to make credible determinations as to financial responsibility for services identified in the Family Care Plan. It is affirmatively not the intent of the CEDARR Program Initiative for Medicaid (or other State programs) to supplant other payers who have a fiscal or fiduciary responsibility for services or supports needed by the child or family.

Under its contract with DHS a RItE Care health plan is responsible for a comprehensive range of benefits and for the overall coordination of care for its members. For children with special health care needs certain of these services are “out of plan”, or beyond the scope of contracted benefits. The State will not pay on a fee for service basis for services for which the health plan is contractually responsible. The CEDARR Family Center must be knowledgeable about RItE Care benefit coverages to help families to effectively implement Family Care Plans. The CEDARR Family Center shall not seek avenues to redirect RItE Care covered services to fee-for-service (FFS) or to move appropriately enrolled RItE Care beneficiaries to fee for service.

It is expected that CEDARR providers will actively coordinate with the health plan. The RItE Care health plan remains contractually responsible for overall care coordination for the child and is committed to remain involved with the member. The CEDARR Family Center must be fully aware of the provider networks of each of the health plans and work to ensure that service recommendations to families identify in-network providers. The Center for Child and Family Health at DHS will provide information needed to support this function.

In the event that the RItE Care plan does not concur with the service recommendations of the CEDARR Family Center, the CEDARR Family Center will communicate and confer with DHS, and if resolution is not achieved, the Health Plan’s appeal process as well as the Department’s fair hearing process may be accessed by the family.

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Some of the Medicaid-eligible (or other) children using CEDARR services will also have some commercial health insurance coverage indicating a third party liability “TPL”<sup>4</sup>. TPL refers to any individual entity (e.g. insurance company) or program (e.g. Medicare) that may be liable for all or part of a Medicaid beneficiary’s health coverage. Under Section 1902(a)(25) of the Social Security Act, DHS is required to take all reasonable measures to identify legally liable third parties and treat verified TPL as a resource to the Medicaid recipient. The CEDARR Family Center is required to work with DHS and with Direct Service and Support providers in identifying other insurance and program coverages. More specific reporting arrangements will be worked out with certified CEDARR providers.

### **2.5.5 Sufficient Knowledge and Skills to Provide Coordination Services**

Staff of CEDARR Family Centers will need to demonstrate the skills and knowledge needed to effectively perform required tasks. Effective coordination with other parties is a central component of the CEDARR Family Center service package. This requires extensive knowledge of community resources, existing systems of care, and the rules and regulations governing State and other public programs. Beyond core knowledge, skills in forging effective linkages and creative synthesis of opportunities for support are essential. Staff of CEDARR Family Centers will be required to successfully complete a State approved training and technical assistance program and to participate in periodic updates and training. This training program will also be focused on ensuring a consistent understanding of the core principles of family centered care and its applications in working with families.

### **2.6 Statewide Capacity**

To be certified, a CEDARR Family Center must demonstrate that it has statewide capacity to provide services to families in geographically accessible and local settings, and may not limit access or participation by geographic or regional catchment area. This is particularly key for Basic Services and Supports. It is not required that specialized clinical services be available at the same locations as basic services. Key is the ability to work with the family to ensure that services are provided. The CEDARR Family Center must demonstrate an effective approach to identifying and dealing with potential barriers for families such as discomfort with meeting in certain settings, transportation, distance from home and the time of day in which meetings are scheduled.

Applicants for certification as CEDARR Family Centers shall identify the ways in which they propose to assure local access to services.

### **2.7 Dissemination of Information About CEDARR Program Initiative**

In initiating and promoting awareness of the CEDARR Program Initiative the State will provide informational brochures explaining the program and identifying certified CEDARR providers

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<sup>4</sup> Further detail on third party liability requirements is contained in the Rhode Island Department of Human Services, Medical Assistance Program Provider Reference Manual, Section 100-60.

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and hold various informational meetings for interested parties (e.g. pediatric primary care providers, other service providers, advocacy groups, parents).

CEDARR Family Centers and certified Direct Service and Support providers may also develop materials which identify or otherwise describe their participation in the CEDARR Program Initiative. Certified providers agree to submit such materials to the State in draft form. The State shall review such materials and determine whether to grant approval for their dissemination.

## **2.8 Bilingual Capability, Cultural Competence**

The CEDARR Family Center must be able to demonstrate how it will be able to provide services to persons for whom English is not a primary language. The CEDARR Family Center must demonstrate in its policies, procedures and practices how it will honor cultural diversity, strengths and individuality within and across all families, including race, ethnicity, environmental and financial supports. The CEDARR Family Center must demonstrate the ability to work effectively in multiple community and cultural settings.

## **2.9 Ongoing Consumer Input for CEDARR Initiative**

Since the Fall of 1998 the Leadership Roundtable for Children and Families with Special Health Care Needs has played a formative role in the design of the CEDARR Program Initiative. The State will again call on the Leadership Roundtable over the next few months of implementation to provide guidance, review and related recommendations. Over the next several months the best means for ensuring ongoing consumer input will be determined.

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## **II. CERTIFICATION PROCESS**

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### **3.1 Submission of Certification Application Required**

To be eligible for reimbursement for CEDARR Family Center supports and services the provider must be certified by the State as a CEDARR Family Center.

Certification applications will be evaluated on the basis of written materials submitted to the State and related pertinent information. The State reserves the right to conduct an on site review and to otherwise seek additional clarifications prior to final scoring. There is no limit to the number of entities which may become certified as CEDARR Family Centers.

In submitting an application for certification as a CEDARR Family Center, the applicant will have had the opportunity to fully review these certification standards and agrees to comply with the requirements as outlined. The State reserves the right to amend the certification standards from time to time, with reasonable notice to participating certified providers and other interested parties.

### **3.2 Instructions and Notifications to Applicants**

This document stipulates the certification standards for CEDARR Family Centers. Certified CEDARR Family Centers are to comply with all performance requirements contained herein and as amended from time to time.

These certifications standards also serve as the application guide. Section V of this document identifies the standards against which applicants will be evaluated. These are divided into five core areas:

- Organizational Structure
- Strength of Program Approach
- Organization of Service Delivery System
- Quality Assurance
- Organizational Capability

Within each of these five areas, specific standards and expectations are identified (e.g. see 5.1.1, 5.1.2, etc.). Applications will be scored on the basis of responses to each of these specific standards and expectations.

Applications are to address each of these areas in the sequence presented. An Application Guide is included in Appendix III to guide the applicant in preparing an application. Program content requirements are contained in the general body of these Certification Standards.

Prior to technical review, submitted applications will be reviewed for completeness and for compliance with core expectations. Incomplete applications will be returned without further review.

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Applicants are advised that all materials submitted to the State for consideration in response to these certification standards will be considered to be Public Records as defined in Title 38 Chapter 2 of the Rhode Island General Laws, without exception.

A Letter of Interest must be submitted by potential applicants at least thirty (30) days prior to submission of a final application. This will ensure that the State is able to keep interested parties fully informed as to any scheduled meetings or program clarifications, modifications or addenda that may be needed. Inquiries, Letters of Interest and completed applications should be directed to:

Sharon Kernan, R.N., M.P.H.  
Assistant Administrator, Community & Planning Services  
Center for Child and Family Health, Department of Human Services  
600 New London Avenue  
Cranston, Rhode Island 02920  
Phone: (401) 462-3392

Completed applications will be accepted for review commencing on July 21, 2000. The State will convene a CEDARR Family Center Application Review Committee to evaluate applications and make recommendations on certification to the Associate Director, Department of Human Services. Applications received by the close of business on July 28, 2000 will be included in the initial review process. Subsequent to that a periodic review process will be established by the State, depending on the submission of applications.

Once a provider is certified as eligible to provide CEDARR Family Center services, the provider shall be enrolled with EDS as a provider of these services. If you have any questions about the enrollment form or enrollment process, please call EDS at 1-800-964-6211. A CEDARR Family Center may represent a coming together of several entities at different physical locations. Nonetheless, each service provider formally affiliated with the CEDARR Family Center to provide CEDARR Family Center services must be enrolled with EDS under the umbrella of the approved CEDARR Family Center.

### **3.3 Informational Meetings for Interested Parties**

Upon initial release of these CEDARR Family Center certification standards and depending on interest, the State will schedule weekly informational meetings for those pursuing certification applications. These meetings will continue until the initial submission date and will provide the opportunity for questions and answers. Whenever possible, applicants should submit written requests for information and clarification. If appropriate, the State will provide written addendums to these standards to further clarify certification requirements.

### **3.4 Certification Period**

Initial certification will be granted on a provisional basis for a two year period, at which point a full certification renewal review will take place. The State reserves the right to certify one or more applicants. In the event of initial provisional certification and upon any subsequent review

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areas of deficiency will be identified and timely corrective action plans required. Certified CEDARR Family Centers are required to notify the State in the event of any material changes in their organizational circumstances or program operations. The State will monitor the performance of certified CEDARR Family Centers and their continued compliance with certification requirements and their programs of care. On the basis of its review and at its sole discretion the State reserves the right to identify deficiencies in performance and/or compliance with CEDARR requirements. Certification may be suspended or terminated for failure to comply with the State requirements.

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## IV. CEDARR FAMILY CENTER AND REQUIRED SCOPE OF SERVICES

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### 4.1. Statement of Intent

CEDARR Family Centers will be established at sites that will be visible in the community, family centered, reflecting parent and professional collaboration, accessible as family friendly locations and have the capacity and expertise to evaluate and support children with special health care needs and their families. CEDARR Family Centers will help families access and blend both formal and informal community and specialized supports necessary for healthy family functioning.

These entities must meet all certification standards and be approved by the State to operate and receive reimbursement as CEDARR Family Centers.

### 4.2 Brief Description of the Role of CEDARR Family Center

The State will certify CEDARR Family Centers to help provide Rhode Island children with special health care needs and their families access to high quality Comprehensive Evaluation, Diagnostic, Assessment, Referral, Re-evaluation services and supports. Because DHS has in the past relied on individual providers to develop EPSDT prescriptions for Medicaid eligible children with special health care needs, there has not been an organized and reliable method through which families could access a full array of appropriate services and supports for their Medicaid eligible children. Thus, at present, families often encounter considerable difficulty and limited support in their efforts to meet the needs of their child and family. The CEDARR Family Center is intended to serve as a family centered, comprehensive source of information, clinical expertise, connection to community supports (e.g. LCCs, Early Intervention, LEAS) and assistance to aid the family to meet the needs of their child.

Each child and his or her family will have the opportunity to voluntarily utilize a CEDARR Family Center to help identify and understand their child's strengths and needs, develop a Family Care Plan for the child and family, and specify and/or navigate provider referrals, funding sources and related services and supports.

A family may choose to use a CEDARR Family Center for assessment, evaluation, and referral only; or to maintain an ongoing relationship using different supports as their needs change over time.

The State will provide reimbursement to certified providers for an expanded set of integrated services for children with special health care needs. In order to be certified as a CEDARR Family Center, it is necessary to meet certain performance requirements and standards as detailed in the CEDARR Family Center certification standards. This section identifies CEDARR Family Center services, which will be reimbursed by the State and expectations for each of those services.

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The CEDARR Family Center must serve all Medicaid eligible children that seek assistance, even if the family is already in another system of care such as LEA, Early Intervention or LCC. If a child is not enrolled in Medicaid the CEDARR Family Center will conduct a preliminary review to inform families of potential Medicaid eligibility and will establish a sliding scale fee schedule based on income for families that are not Medicaid eligible.

The CEDARR Family Centers will provide both (a) basic services and supports to families and (b) specialized clinical evaluation and care coordination services. At the outset the CEDARR Family Center will work with the child and family to determine current circumstances, continuing needs and reasonable next steps. On this basis a CEDARR Family Care plan will be developed, and a decision regarding continuing Family Care Coordination services may be made.

In all cases the CEDARR Family Center will assist the family in choice of a provider and will help to coordinate arrangements for service(s). The CEDARR Family Center shall continue to work with the family to support efforts to gain access to needed services and to track receipt of services and progress in meeting treatment goals.

#### **4.3 Scope of Required Services**

In order to be certified, an applicant must demonstrate its ability to provide both basic and specialized services in accordance with all of the requirements contained in these certification standards. These services may be provided by staff directly employed by the CEDARR Family Center or through contract personnel, independent contractors and practitioners or by subcontract. The ability of the CEDARR Family Center to provide the full range of services to CEDARR Family Center clients in all geographic areas may be based on formal agreements between the lead agency of the CEDARR Family Center and other entities. In all cases certified CEDARR Family Centers must be able to provide the full range of basic services to children with special health care needs and their families across the full spectrum of special health care needs. Each CEDARR Family Center will also provide specialized services in each of the identified areas. Each applicant will clearly demonstrate the ability to provide services in each of the specialty area(s). The State reserves the exclusive right to determine the CEDARR Family Center's capacity to provide services in each specialty across all disability areas.<sup>5</sup>

CEDARR Family Centers will be certified on the basis of their demonstrated ability to provide the required range of basic services and to provide specialized clinical expertise in a manner that is fully family centered and reflective of the community resources available in the community of residence of the child and family.

The required scope of CEDARR Family Center services is:

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<sup>5</sup> A core principle of the CEDARR Program Initiative is that each child be viewed as unique, with every care plan individually determined. Multi-specialty diagnostic and referral capacity is critical to respect the fact that many children have nuanced, multiple diagnoses.

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Basic Services and Supports - These services will be available through all certified CEDARR Family Centers.

*Service 1:* Initial Family Contact

*Service 2:* Initial Family Assessment and Supports, including:

- Provision of special needs resource information
- System mapping and navigation, and
- Resource identification
- Eligibility assessment and application assistance
- Peer family support and guidance

Specialized Services - These services will be provided based on certified clinical expertise.

*Service 3:* Crisis Intervention - Clinical Triage and Follow-up Care Coordination

*Service 4:* Specialty Clinical Evaluation and Treatment Consultation

*Service 5:* Family Care Plan Development, Review and Revision

*Service 6:* Family Care Coordination

Each CEDARR Family Center will have demonstrated expertise in at least the following areas:

- Autism spectrum disorders
- Behavioral health
- Severe medical or physical disabilities
- Services to children who rely on medical devices to sustain life,
- Developmental disabilities

## **4.4 Services Description**

### **4.4.1 Initial Family Contact, Initial Family Assessment and Basic Services and Supports**

#### **4.4.1.1 Initial Family Contact**

In most cases the initial contact with a CEDARR Family Center will be a routine inquiry. A family may be seeking basic information and not wish to have further involvement with the CEDARR Family Center at that time. Or, a family may require support and guidance to determine the appropriateness of further contact with the CEDARR Family Center, outlining the particular circumstances surrounding a child, inquire as to the Center's role, associated fees etc. In many cases, as a conversation proceeds, the Initial Family Contact will blend into, and become part of, the Initial Family Assessment.

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In the event of a crisis or an urgent situation the CEDARR Family Center is expected to respond provide appropriate Clinical Triage services (see Section 4.4.3 Crisis Intervention services). Related direct services would be reimbursable to the relevant provider. In routine situations families shall be scheduled for intake appointments within 14 calendar days of initial request.

#### **4.4.1.2 Initial Family Assessment**

The Initial Family Assessment, including the Initial Family Contact, encompass the Basic Services and Supports available to a family upon entry into the CEDARR Program Initiative. These services may be provided over the course of one or more visits with the child and family in the home, a community setting or at the CEDARR Family Center site, as determined by the family and the CEDARR Family Center.

At initial contact (telephone or visit) an Initial Family Assessment (IFA) will be initiated. Families may contact the CEDARR Family Center for a broad array of reasons. Concerns may range from efforts to obtain a clear diagnosis, to the problems of navigating the various programs of financial support and eligibility. Children may present with multiple problems and/or diagnoses. Families will have a mix of strengths and needs.

The goal of the IFA is to meet with the family to develop a working profile that forms the foundation for next steps. In its application for certification the CEDARR Family Center shall identify its approach to this assessment. The assessment shall include such areas as:

- Assessment of urgency
- Developmental and diagnostic history
  - Physical health
  - Behavioral health
  - Cognitive development
- Current interactions with the care system, history of interactions; involvement with a pediatrician or other primary care provider.
- Participation in, involvement with any other programs (e.g. Special education, Early Intervention, Rite Care, SSI, Katie Beckett, DCYF programs such as LCC/CASSP, CIS, or others)
- Family circumstances, strengths, needs, supports
- Social, community, spiritual involvements and supports
- Knowledge of, linkage with, advocacy groups, professional associations (e.g. Parent Support Network, LCC/CASSP, Family Voices)
  - Current insurance status and needs

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- Potential eligibility for various public programs and/or community supports.

#### **4.4.2 Basic Services and Supports**

In addition to the Initial Family Assessment, the CEDARR Family Center will provide basic services and supports. These include:

- **Provision of Special Needs Resource Information**—CEDARR Family Centers will have the necessary expertise, resources and knowledge base to inform families and to enable families to inform themselves about specific disorders, including etiology, prognosis, research findings, treatment and provider options. Information must be provided in a culturally competent manner. The objective is to enable the family to be as fully knowledgeable as possible.
- **System Mapping and Navigation**—Tailored to the needs of the child and family, the CEDARR Family Center shall fully inform the family of the whole system of support, services, assistance and legal rights available to children with special health needs and their families. The family shall be provided with assistance in creating their own personal map to navigate the system. Particular assistance shall be offered with the technical and administrative complexities confronted by families such as understanding the eligibility requirements, service coverages and related policies of existing programs (including Medicaid), accessing insurance coverage, and interagency coordination issues.
- **Resource Identification**—Each family's strengths and challenges are different. The CEDARR Family Center shall help families identify the resources that are available to them beyond the scope of Medicaid. Formal and informal resources shall include but not be limited to: parents, family members, service providers, grants, social programs, support groups, funding options, school based opportunities, and recreation available to children with special health care needs and their families.

A core objective is that to the degree possible families are informed of opportunities and supports that are closest to home, that are the least restrictive and are keyed toward integration in the home and community. There is emphasis on the use of informal, natural community supports as a primary strategy to assist individuals and families.

- **Eligibility assessment and application assistance**—The CEDARR Family Center will assist families to identify and understand the eligibility criteria for various programs which may provide a source of support for children with special health needs and their families (e.g. Medicaid, LEA Special Education, LCC, Early Intervention). The CEDARR Family Center will assist a family in determining potential eligibility and, if desired by the family, will assist the family in making application.

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- Peer Family Support and Guidance—A critical resource for families can be support and guidance from peer family members. Peer family support and guidance can be invaluable to parents, providing information and skills which assist in understanding and coping with the family stressors associated with the child's special health need and in better understanding how to best work to meet the needs of their child.

Peer family support and guidance may be accomplished by linking parents with peers in one-to-one meetings or may take the form of family support group meetings.

CEDARR Family Centers shall develop formal written agreements with appropriate parent support and information centers whose missions are focused on the specialized health care populations (e.g. Rhode Island Parent Information Network, Parent Support Network, Family Voices, etc.) to enhance their efforts to provide basic services and supports.

#### **4.4.3 Crisis Intervention Services**

CEDARR Family Centers must be accessible 24 hours a day by phone. Any child, family member or professional can call or visit a CEDARR Family Center during business hours in the event of a crisis.

Children known to the CEDARR Family Center (e.g. an Initial Family Assessment has been completed) will be clinically triaged through the CEDARR Family Center protocol for crisis intervention. All CEDARR Family Centers will need to have a 24 hour protocol that is consistent statewide and approved by the State. CEDARR Family Centers must present explicit protocols for handling cross coverages during the day and during off-hours. Intervention strategies may vary from Family Center to Family Center. In all instances the family will be educated to understand what defines a crisis and instructed as to what to do in an emergency. All Family Care Plans will specify what to do in a crisis so there is understanding and agreement by all involved parties. Direct Service Providers may be specified in the Family Care Plan as the appropriate first contact in an emergency. They will need to agree to 24 hour a day availability if they are to assume this role.

In any instance where someone is not sure how to proceed, any family or professional can always call a CEDARR Family Center 24 hours a day to ask for instructions on what to do in a crisis.

The CEDARR Family Center is not expected to be a direct provider of crisis intervention services. Existing or newly emergent crisis intervention service providers are to be accessed as appropriate. The CEDARR Family Center must be able to provide two specific services related to crisis intervention. These are:

- Clinical Triage and
- Crisis Follow-up Care Coordination.

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Clinical triage must be performed by a licensed Master's level clinician. Telephone access to the triage clinician must be available 24 hours per day within fifteen minutes of an initiating phone call, day or night. Working with established protocols and in interaction with the family, the triage clinician will make an assessment and determination of appropriate action. In the event of a specific referral for immediate intervention, the triage clinician will initiate referral and convey relevant clinical information to the referral provider.

It is at the point of crisis that the services of the CEDARR Family Center can be most instrumental in positively affecting the outcome of the episode for the child and family. Clinical triage may serve to help trigger and support immediate intervention. This intervention may take various forms (e.g. mobile community based treatment, emergency room consultation). It is in the several hours and day or two immediately following the point of crisis that the family will likely need aid and assistance in understanding options and securing needed services and supports. Crisis Follow-up Care Coordination is a required service capacity of CEDARR Family Centers. This service includes direct follow-up communication with clinical staff of the direct service provider of crisis intervention services, collaborative work with the family in determining next steps and arranging for community based services as appropriate. Crisis Follow-up Care Coordination must directly involve and be closely overseen by a licensed clinician; additional staff of the CEDARR Family Center may be involved.

All CEDARR Family Centers must demonstrate the capacity to triage any crisis call and provide direct crisis intervention supports across areas of special need. The CEDARR Family Center will be responsible for understanding where to connect the child and their family. Again in all instances the disposition of a crisis must be signed off by a licensed clinician.

#### **4.4.4. Specialty Clinical Evaluation and Treatment Consultation**

##### **4.4.4.1 Specialty Clinical Evaluation**

On the basis of the Initial Family Assessment it may be determined that it is appropriate to arrange for an in depth specialty clinical evaluation, assessment and diagnosis. This clinical evaluation will guide the development of the Family Care Plan. The specialty clinical evaluation will be performed by the CEDARR Family Center-affiliated clinical specialist(s)<sup>6</sup>. These services will be reimbursed by Medicaid according to the prevailing fee schedule. Re-evaluation and other clinical face-to-face encounters may occur as clinically indicated.

##### **4.4.4.2 Treatment Consultation**

Involvement of the clinical specialist is expected to be ongoing rather than a one time event at the point of evaluation. The work of the clinical specialist will assist in the development, review, and assessment of the Family Care Plan. The Family Care Plan shall state measurable goals, objectives, and outcomes. The clinical specialist will regularly and periodically participate in

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<sup>6</sup> In unusual circumstances referral may be made for evaluation to a clinical expert with specialized skills beyond those of the CEDARR Family Center.

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case conferences and reviews in which child and family progress is assessed, and Family Care Plans revised, as appropriate.

#### **4.4.5 Family Care Plan Development and Family Care Coordination**

Family Care Plan development and Family Care Coordination will be paid as two distinct services. Family Care Plan development is a one time only service. A condition for payment is that an Initial Family Assessment has been completed. The IFA is presumed to serve as the primary basis for development of the Family Care Plan. In this respect the Family Care Plan builds on prior interactions with the child and family and marks the completion of one phase of work with that family.

Family Care Coordination can be elected by the family and approved by the CEDARR Family Center as an ongoing support, where needed. It is affirmatively not intended that each Family Care Plan will result in the formation of a Family Care Coordination relationship or that such relationships prove to be permanent. The affirmed purpose of the Family Care Coordination relationship is to promote fully realized family independence, and the success of all CEDARR Family Centers will be judged in this light.

##### **4.4.5.1 Family Care Plan**

Family Care Plans will be tailored to the unique circumstances of the child and family. Development of the Family Care Plan may represent the end of the family's involvement with the CEDARR Family Center or active involvement may continue. In the latter case, The State is prepared to reimburse the CEDARR Family Center for Family Care Coordination services (see below). The level of intensity of CEDARR Family Center Care Coordination Services may vary from child to child - and over time for the same child.

To be eligible for reimbursement, the Family Care Plan must be developed with and signed by the child's parent(s) or authorized guardian. A Family Care Plan may include a direct service plan including services by CEDARR certified direct services and supports providers. This direct service plan must also be signed by the provider in order for the CEDARR Direct services to be reimbursed for those services.

##### **4.4.5.1.1 Principles for Development of the Family Care Plan**

Based on the Initial Family Assessment, the specialty clinical evaluation (if applicable) and other pertinent information, the CEDARR Family Center will work with the family to assess the child's strengths and challenges as a whole, and to review the diagnosis, evaluation, care and referral options for the child and the family as a whole. On this basis and in collaboration with the family, the Family Care Plan will be developed.

General principles for the Family Care Plan include, but are not limited to:

- The Family Care Plan shall be designed with the family and as appropriate the child to assist the family in its efforts to successfully (a) address the clinical care

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needs of the child, (b) support the family in its efforts to maintain a supportive and therapeutic home environment and (c) to manage the complex tasks of gaining access to (and financial eligibility for) needed medical, social, educational and other services.

- Plans shall be individualized, detailed, flexibly designed and meaningfully related to cultural and community context.
- Assessments and care plans shall identify and build on strengths. The role of family and positive community supports is critical.
- The Family Care Plan will be developed with the family and, as appropriate, in coordination with existing community resources (specifically including LCCs, Early Intervention and LEAs).
- Plans are based on the assessment information, on the strengths and needs of the child and family, and on clinical protocols which indicate the level, types and intensity of care considered medically necessary and appropriate. Each is based on circumstances identified in the assessment and directed toward the achievement of identified and measurable goals and objectives. Support shall be targeted to occur in the most natural environment and in the least restrictive setting appropriate. The plan shall identify objectives which represent decision or review points for the re-evaluation of service level, types and intensity.

The Family Care Plan shall:

- Provide the family with an organized and focused plan of approach for its own use which may not depend on further care coordination activities or Direct Service and Support activities, or
- Call for active Family Care Coordination activities by the CEDARR Family Center to support both clinical care plans and other supportive and assistive services.

#### **4.4.5.2 Family Care Plan Review, Revision and Recommended Action**

In the event that a Family Care Plan includes a direct service component it will also include identified goals and objectives and may include recommended authorization for CEDARR related services. Progress in achieving these goals and objectives and the continuing appropriateness of the Family Care Plan as written must be regularly reviewed and modified as appropriate. Family Care Plan Review will be reimbursed once per approved plan period.

In no event shall a plan including direct services or Family Care Coordination be approved for a period greater than six months. In many cases it may be appropriate for the approval period to be shorter. The outcome of the Family Care Plan Review will be a formal recommendation to

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the State as to continued approval or modification of the Family Care Plan. The Family Care Plan Review must be developed and signed by the child's parent(s) or authorized guardian.

Depending on the circumstances the Family Care Plan may or may not involve monthly Family Care Coordination by the CEDARR Family Center. The task of Family Care Plan Review and Research will vary depending on whether or not there, as been ongoing Family Care Coordination. In cases involving ongoing Family Care Coordination, the Family Care Plan Review and Revision serves as a point of systematic review to assess progress and status. The CEDARR Family Center has maintained a continuing involvement with the child and family. In this event the reimbursement is more nominal, marking a formal point in time (Plan Review and Revision with Family Care Coordination).

In cases where there is not ongoing Family Care Coordination, greater effort will be required to conduct the review (Plan Review and Revision without ongoing Family Care Coordination) in that the CEDARR Family Center must invest effort to re-familiarize itself with the circumstances of the family and make recommendations accordingly.

#### **4.4.5.3 Family Care Coordination**

Family Care Coordination incorporates a range of activities supportive of the initiation, tracking, re-evaluation and modification of Family Care plans. Family Care Coordination commences as a paid service at the point at which a Family Care Plan which includes ongoing involvement on the part of the CEDARR Family Center is signed by all parties. Family Care Coordination incorporates various elements which are present in "Targeted Case Management" activities presently supported with Medicaid funds. It is the intent of the State that Family Care Coordination not duplicate other services supported with Medicaid dollars. Families may elect either Family Care Coordination through a CEDARR Family Center or case management services which may be available through another public program. Family Care Plans must be clear that the family understands this choice at the point of signing the plan. Components of Family Care Coordination include:

- Services which assist individuals to gain access to identified needed health care services (e.g. referral coordination, follow-up, personal support to the family, phoning to make appointments, acting as a liaison for the family with providers, Medicaid, other State and local public agencies, existing systems of care, insurance, fact finding, interpretation of information). Healthcare is defined broadly here to include any professional service or support necessary to achieve the child's Care Plan, including non-traditional basic services and supports known to minimize the need for hospital care and long term residential placements.
- Regular follow up with the family, Direct Service and Support providers and other involved parties to ensure continued care per the care plan, identification of emergent problems or needs, working with health plans, further coordination with State and local public agencies to support development of a unified plan.

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- Monitoring and re-evaluation of Family Care Plans. Family Care Plans will specify that services be delivered as close to home as possible and in the least restrictive setting. They will include such components as parent training and support. The intensity of services shall be tied to level of need and anticipated outcome. Family Care Plans are to include measurable goals and objectives which inform Family Care Plan Review and modification. Family Centers will be data and outcomes driven in performing periodic assessments and re-evaluations of each child and family following implementation of the treatment plan.

Family Care Coordination Services will be reimbursed at two levels of intensity:

- Level I: Payable for the first month of Family Care Coordination services immediately following completion of the Family Care Plan. This supports a higher level of intensity associated with initiation of a Family Care Plan.
- Level II: This is a monthly Care Coordination fee paid after the first month and for the duration of the active Family Care Plan.

#### **4.5 CEDARR Family Center Service Performance Requirements**

Performance requirements are identified for each of the reimbursed CEDARR Family Center services.

##### **Service 1: Initial Family Contact**

When a family first contacts a CEDARR Family Center that contact may be one of three primary types. The CEDARR Family Center must have protocols and staffing capacity to respond to each. These three are:

- Informational inquiry—The family seeks general information about the nature and scope of CEDARR Family Services. There is no further immediate contact with the family.
- Imminent risk or urgent need—This is a situation requiring prompt intervention on an immediate basis or within 24 hours. This would be based on a contact with family or child indicating a situation in which a child poses an imminent risk to self or to others; and/or where there appears to be imminent risk of an out of home placement. In this case the family should have immediate access to a CEDARR Family Center licensed clinician for Clinical Triage.
- Routine initial service contact—The family contacts the CEDARR Family Center seeking services on a non-urgent or routine basis. This leads to Initial Family Assessment and Basic Services or supports.

Initial contact with a family by staff of the CEDARR Family Center is a critical first point of entry during which the relationship between the family and the CEDARR Family Center is

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established and in some ways permanently defined. Substantial training in the family centered model, in clinical issue spotting and in sensitivity and awareness to the emotional state of the caller is essential for this to serve as the foundation for a positive working relationship between the family and the CEDARR Family Center.

In many cases the Initial Family Contact with a CEDARR Family Center will be an informational inquiry. In other cases this initial contact begins the process of involvement with a family and may be more involved and time consuming. In this event, much of the information from this Initial Family Contact will contribute to completion of the Initial Family Assessment. In more urgent cases, the Initial Family Contact may lead to a Clinical Triage.

In the case of imminent risk or urgent need, Crisis Intervention services must be able to be provided immediately in the form of Clinical Triage and arrangement for Crisis Intervention services by a direct service provider. The CEDARR Family Center will be reimbursed for provision of those Clinical Triage services.

In a routine initial service contact, the call may progress to a more in depth discussion regarding a child's condition and needs and some limited family supports may, in fact, be provided over the phone. In the course of this discussion some portions of Service 2, Initial Family Assessment and Supports, may be completed.

## **Service 2: Initial Family Assessment (IFA) and Supports**

Components of this service include the Initial Family Assessment and Basic Services and Supports. These include: Provision of Special Needs Resource Information, System Mapping and Navigation, Resource Identification, and Peer Family Support and Guidance.

**Timeliness:** Initial Family Assessment and Supports may be accessed on an urgent or routine basis.

In the event of an imminent risk or urgent need situation, telephone based Clinical Triage (see below) must be available within fifteen minutes of the initial contact by the family in which this urgent situation has been identified.

In an urgent situation, Crisis Follow-up Care Coordination services must be able to be provided within 24 hours of identification of the situation or request by the family.

Routine appointments must be offered to take place within 14 calendar days of request by the family.

**Frequency:** Initial Family Assessment and Supports can be billed one time per child by a CEDARR Family Center within a two year period; this service cannot be billed by a CEDARR Family Center until 6 months have elapsed since the termination of Family Care Coordination services. Contacts, assessments and basic supports

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on an extended basis are assumed to be part of ongoing Family Care Coordination.

**Duration:** Expected duration is eight to ten hours<sup>7</sup>. This can include telephone contact, direct face-to-face contact with the child and family, and related case review, coordination and follow up with other parties. This service may be provided over the course of one or more sessions with a child and family. A face-to-face contact with the child and family totaling a minimum of two hours is required.

**Outcome:** The CEDARR Family Center shall have completed a comprehensive Initial Family Assessment and will have provided, as needed, Family Supports in the areas of provision of special needs resource information, system mapping and navigation, resource identification and peer family support and guidance. Family members shall have the benefit of meeting with peer families and learning skills and information which assist in understanding and coping with the family stressors associated with the child's special health need and other family support needs.

**Location:** Services are to be provided at the CEDARR Family Center or other appropriate site (e.g., home or other community setting).

**Staff:** This service must be provided by qualified trained staff<sup>8</sup>. Under the supervision of an appropriate licensed clinician, the Family Service Coordinator may perform various portions of the IFA. The licensed clinician must have a face-to-face encounter with the child and family of at least 30 minutes. The IFA must be completed under the direction of and be signed by the licensed clinician.

### **Service 3: Crisis Intervention**

Crisis Intervention represents services undertaken to address a situation of identified imminent risk and/or urgent need. In the event of a crisis the role of the CEDARR Family Center is to provide guidance and coordination assistance to support effective stabilization of the situation. Crisis intervention is an immediate response to a situation of imminent risk and/or urgent need. In response to an identified crisis the CEDARR Family Center will be prepared to undertake two components of crisis intervention services: clinical triage and crisis follow-up care Coordination.

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<sup>7</sup> Here and elsewhere in these Certification Standards certain norms are stated with regard to expected duration of effort or maximum allowable length of time for a Family Care Plan. These stated norms are subject to adjustment over time.

<sup>8</sup>Qualification requirements for CEDARR Family Center staff are reviewed in Section V. This discussion assumes that the staffing complement includes a Family Service Coordinator and an appropriate licensed clinician licensed at the independent practice level as a licensed clinician (e.g. Licensed Independent Clinical Social Worker, Nurse Practitioner, Psychologist, approved Master's level counselor).

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The objective of these services is assess the situation, take appropriate and family-agreed upon actions to engage needed direct services to stabilize the situation. Stabilization means that the family and the care providers have agreed upon a plan for short-term management that all agree is workable and which respects principles emphasizing services that are family centered and are provided in the least restrictive appropriate manner. Initial action for the CEDARR Family Center is a contact made by the family which initiates clinical triage activities. Crisis intervention is then continuing until direct services are in place, crisis follow-up care coordination has occurred and a short term management plan is agreed to and supported.

**Timeliness:** Crisis intervention is an immediate response to an situation of imminent risk and/or urgent need, 24 hours a day. Crisis intervention in the form of clinical triage by an appropriate licensed clinician is to be available within fifteen minutes of an initiating phone call, day or night.

**Frequency:** Crisis intervention will be available as many times as is necessary. It is expected that once the child and family are known to the CEDARR Family Center, the CEDARR Family Center and Certified Providers of direct services and supports will do everything reasonably possible to avoid the escalation of a child's and or family's needs to an emergency level. Recurrent emergencies will trigger a timely re-evaluation of the Care Plan.

**Duration:** Crisis intervention can vary depending on the nature of the crisis, knowledge of the family, the location of the child and the nature of his/her special health care need, associated needs of the family members, time of day, involvement of other legal entities, and availability of appropriate supports and services.

If an emergency or urgent situation is the first encounter of the child and family with the CEDARR Family Center more time may be necessary to manage the crisis.

The duration of the crisis intervention is expected to typically require a total of four to six hours of effort; such effort may be spread out over one or more days.

**Outcome:** The outcome of crisis intervention is stabilization of the situation such that imminent risk of harm or avoidable out of home placement has been ameliorated. The child and family shall be out of crisis at the point where, as signed-off on by a licensed clinician, that their medical status is stabilized and in instances of behavioral health they are not considered a threat to themselves or others; and when the CEDARR Family Center clinician and family conclude that they have a plan of support to meet the urgency of the situation. An important objective is that an unnecessary hospitalization has been avoided, or in the event of a hospitalization at the point of crisis, that a timely discharge to the community has been effected through implementation of a community based program of support.

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**Location:** Crisis intervention services can happen over the phone, at a CEDARR Family Center, at the site of a CEDARR Certified Provider, the child's home or legal residence, a hospital or at any other appropriate community location.

**Staff:** Once a crisis is assessed by the CEDARR Family Center, a licensed on-call clinician must be immediately contacted to assure the implementation of planned interventions. Staff coverage will be available 24 hours a day with reasonable backup systems to assure timely response. CEDARR Family Centers can coordinate with other CEDARR Family Centers to triage emergencies. All Family Care Plans will specifically designate who is responsible for an emergency. Children receiving care from a direct care provider may necessitate immediate contact to that individual. In all instances this will be specified in advance in the Family Care Plan.

**Service 4: Specialty Clinical Evaluation and Treatment Consultation**

**Service 4a Specialty Clinical Evaluation**

Specialty clinical evaluation is intended to provide for a comprehensive diagnosis and assessment that will be used in development of the Family Care Plan.

**Timeliness:** Specialty clinical evaluation must be initiated within fourteen business days of initial request.

**Frequency:** Specialty clinical evaluation and re-evaluation may take place as is clinically indicated.

**Duration:** As per existing Medicaid policy.

**Outcome:** Comprehensive diagnosis and assessment; clinical information that will be strength based, family centered, community based and culturally competent which will inform development and monitoring of the Family Care Plan.

**Location:** Services are to be provided at the site of clinical expert, at the CEDARR Family Center or other appropriate site.

**Staff:** Service must be provided by approved clinical specialist(s) per CEDARR Family Center certification.

**Service 4b. Treatment Consultation**

Treatment consultation represents the continuing involvement of the clinical expert in review and monitoring of progress of CEDARR Family Center clients. This may take the form of participation in care conferences or reviews in which more than one child is reviewed at a time or it may be an individual treatment consultation. The CEDARR Family Center will make demonstrable efforts to involve the child's primary care provider or other relevant primary

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physician and to coordinate a consultation between other specialists who have provided or are currently providing treatment consultation to the child and family. The State will also reimburse the CEDARR Family Center for the treatment consultative services of these providers as billed through the CEDARR Family Center.

**Timeliness:** Scheduled as needed.

**Frequency:** As per Family Care Plan or on an as needed basis.

**Duration:** These services are reimbursed incrementally on the basis of 30-minute service units.

**Outcome:** Systematic clinical expert review that will be strength based, family centered, community based and culturally competent of progress in meeting Family Care Plan goals and objectives, specific recommendations for plan modifications as appropriate.

**Location:** Services are to be provided at the site of clinical expert, the CEDARR Family Center or other appropriate site

**Staff:** Service must be provided by approved clinical specialist(s) per CEDARR Family Center certification

**Service 5: Family Care Plan Development, Review and Revision**

This service relates to both initial development of the Family Care Plan and to periodic review and revision.

**Service 5a: Family Care Plan Development (Initial Family Care Plan)**

To be eligible for reimbursement, the Family Care Plan must be developed with and signed by the child's parent(s) or guardian. The Family Care Plan is to be comprehensive, addressing the strengths and needs of the whole child and family. This requires a multi-dimensional assessment and planning process tailored to the unique circumstances of the child and family and not constrained by a presumptive diagnosis or source of funding for services. At the same time development of the Family Care Plan must be cognizant of and include all agencies that are involved with the child and family. For example, if the child has, or is being considered for, an IEP or will receive services from a school district pursuant to Section 504 or the ADA, then the school district's special education planning personnel must be involved in the development of the Family Care Plan. When this occurs, the Family Care Plan must be developed such that it conforms with relevant State and Federal laws and regulations regarding educational planning for children with special needs.

For a child being served by a CEDARR Family Center the Family Care Plan must be the "master plan" that incorporates all other planning documents and results in a single coherent plan with relevant component parts. All rights that families have to challenge planning processes with any

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of the relevant agencies of State or local government are preserved in the CEDARR Family Care Plan development process.

**Timeliness:** Development of the Family Care Plan will in most cases involve several steps and interactions with and participation by a number of parties (e.g. family, clinical experts, other CEDARR Family Center staff, direct treatment provider, peer family other coordinating entities such as DCYF, LEA, LCC, Early Intervention, etc). For these reasons no specific time frame is attached to development of the Family Care Plan. However, a family is entitled to prompt action on the part of the CEDARR Family Center so that services can be initiated.

An interim Family Care Plan must be presented to the family within ten business days of a family's written request for such a plan. A family can make such a request at any point following a family care plan development meeting in which the family has been a full participant. Such an interim plan will identify services being initiated at that point; it will further delineate and provide a status report on plan areas which continue to be developed and will identify the time frame for completion. Families are to be clearly advised of their right to make such a request.

**Frequency:** Family Care Plan development can be reimbursed only one time within a two year period.

**Duration:** Not applicable to Family Care Plan Development itself. The maximum period which a Family Care Plan can cover is six months. Shorter time periods will frequently be appropriate. A Family Care Plan can be modified or extended for a period beyond the initial period.

**Outcome:** A comprehensive Family Care Plan developed with and signed by the family representative and the CEDARR Family Center clinical expert.

**Location:** Development of the Family Care Plan can occur at the CEDARR Family Center, the family's home or other appropriate site.

**Staff:** If the Family Care Plan includes any direct treatment services or continuing Family Care Coordination services the Family Care Plan must be signed by the approved clinical expert(s) per CEDARR Family Center certification and by the certified direct care provider.

#### **Service 5b: Family Care Plan Review and Revision**

Once a Family Care Plan has been established it is to be systematically reviewed on a periodic basis. This review will assess progress in meeting the goals and objectives established in the initial Family Care Plan and identify changes in family strengths and needs, and evaluate the performance of direct service providers. Based on this review the Family Care Plan will be extended, terminated, and or revised. The family will participate in this review.

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- Timeliness:** A CEDARR Family Center Family Care Plan including direct services or Family Care Coordination cannot be approved for a period greater than six months. In many cases the plan will be for a period less than six months. An expiring Family Care Plan must be rigorously reviewed by the CEDARR Family Center, the family and other key participants not later than 30 days prior to expiration. At that point it may be determined that no further services are needed. If services are to be continued, an updated or revised Family Care Plan will be completed not later than 21 days prior to expiration.
- Frequency:** Family Care Plan Review and Revision will not be reimbursed more than four times within a twelve month period. Frequency will depend on the approved length of the Family Care Plan.
- Duration:** Approximately four hours.
- Outcome:** An updated and revised Family Care Plan developed with and signed by the family representative and the CEDARR Family Center clinical expert.
- Location:** Development of the Family Care Plan can occur at the CEDARR Family Center or other appropriate site.
- Staff:** If the Family Care Plan includes any direct care services or continuing Family Care Coordination services the Family Care Plan must be signed by the approved clinical expert(s) per CEDARR Family Center certification and by the certified direct care provide.

**Service 6: Family Care Coordination**

Family Care Coordination services incorporate a range of activities directed at the initiation, tracking, reevaluation and modification of Family Care Plans. Staff providing this service shall have the demonstrated ability to coordinate all aspects of the child's total health care. Health care is defined broadly here to include any professional service or support necessary to achieve the Family Care Plan.

- Timeliness:** Family Care coordination commences at the point at which a Family Care Plan, which includes ongoing involvement of the CEDARR Family Center, is signed by all required parties, including the CEDARR Family Center representative.
- Frequency:** Monthly. Family Care Coordination is paid on a per month basis. Services for less than one month will be reimbursed on a pro- rated basis.
- Intensity:** Family Care Coordination services are reimbursed at two levels of intensity:
- Level I: Payable for the first month only of Family Care Coordination services immediately following completion of the Family Care

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Plan. This supports a higher level of intensity associated with initiation of a Family Care Plan.

Level II: This is a monthly Care Coordination fee paid after the first month and for the duration of the active Family Care Plan.

NOTE: It is affirmatively not intended that each Family Care Plan will result in the formation of a Family Care Coordination relationship, or that such relationship be permanent.

**Duration:** The maximum duration for a single plan is six months. Shorter periods may frequently be deemed appropriate. There is no limit on the number of successive medically necessary care plans, which may be approved for a given child.

**Outcome:** Effective assistance in gaining access to needed services, regular follow up with family, direct treatment providers, identification of emergent needs and problems, effective monitoring and re-evaluation of family care plans, parent training to gain self determination skills and reduced dependence on formal care coordination.

**Location:** In the community, at the home, the CEDARR Family Center and other sites deemed appropriate.

**Staff:** Licensed clinician and Family Service Coordinator.

#### **4.6 CEDARR Family Care Plan, Coordination with Direct Service and Support Provider and Authorization of Services**

##### **4.6.1 Relationship between CEDARR Family Center and Direct Service and Support Provider**

Among the family's choices for specialized services is selection of a Direct Service and Support provider from those certified by the State.

The CEDARR Family Center and Direct Service and Support provider(s) will work together to facilitate initiation of Direct Service and Support. The CEDARR Family Center will have conducted an Initial Family Assessment and, as needed, a current clinical evaluation. On this basis a preliminary Family Care Plan is developed.

It is anticipated that this will be an interactive process with active communication between the CEDARR Family Center and the Direct Service and Support provider.

In the course of Family Care Coordination, on a regular and continuing basis, the CEDARR Family Center will collect and assess progress updates from families and Direct Service and Support providers, will collect and analyze both utilization and outcome data, and will incorporate this information in the re-evaluation of the Family Care Plan, as necessary. On an aggregate basis, the CEDARR Family Center will provide the State with reports on a quarterly basis describing activity, service utilization, and outcomes for all children and families having a

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relationship with the Center. On not less than an annual basis, the Center will provide the State with an assessment of each Direct Service and Support provider to whom a referral has been made within the previous twelve months, describing the number of referrals, apparent programmatic strengths and weaknesses of each, as well as a comparative analysis of outcomes achieved.

#### **4.6.2 Expectations for the Family Care Plan and the Direct Service and Support Component**

The Family Care Plan is designed to address the specific needs of an individual child and family. The plan itself may specify a treatment intervention and modality that has a demonstrated clinical effectiveness. The care plan must have clearly identified goals and objectives that are measurable and appropriate to the child and family identified strengths and needs. Coordination with other ongoing service and support activities and agencies (e.g. Early Intervention, LCCs, Special Education) shall be clear. Adequate background information on the child and family shall be included.

Areas the proposed Family Care Plan shall address include:

- **Diagnosis**— The child’s diagnosis shall be clearly identified. This may be quite recent and obtained through the CEDARR Family Center or by other means. Documentation shall identify who made the diagnosis, the basis for the diagnosis, and when the diagnosis was made.
- **Diagnostic and treatment history**—The approved treatment plan shall include information on the services that have been provided previously (this should include clinically information relevant to plan development and historical information sufficient to fully inform assessment and planning). Information shall be present regarding any other providers that have been involved with the child and family (e.g. child psychiatrist), other treatments that have been tried or considered, and the sequence of events leading to this submission?
- **Assessment**—Shall include a thorough identification of the specific needs of the child and family. This includes the Initial Family Assessment, the clinical evaluation, as well as other pertinent information developed by the Direct Service and Support provider. Components of the assessment shall be identified, dependent on approved releases signed by the family (e.g. parent interview, child observation, conversations with school, other community based agencies or providers). If one has been developed, the IEP, IFSP, and/or CASSP Individual Service Plan shall be attached and the assessment shall identify the services being received through the schools. Problem behaviors shall be identified and order of importance or priority indicated. The involvement of the family and the preparedness of the family (including extended family and/or other potential caretakers) to participate in treatment shall be indicated. The information and training needs of family members will be assessed to inform Family Care Plan components intended to increase the ability of the family to function in the family

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centered program. This shall include both parents whenever possible even if they are not living together. If appropriate, concerns that the child is at risk for out of home placement without this treatment plan shall be noted.

- **Direct Services and Support**—The plan shall be clearly based on the assessment. The prioritization of goals and objectives in the plan shall be clearly grounded in the assessment and in clinical guidelines, which identify the level, type and scope of service. Goals and objectives need to be specific and measurable. It shall be clear how it will be determined whether or not goals have been achieved. The role for parents in the plan shall be identified. The plan shall include a parent training and support component. The plan shall meet the State's criteria for family centeredness. The proposed plan must be signed by the parent unless there is documented reason why this is not appropriate (e.g. the child is in DCYF custody; in this case the appropriate person shall sign). The overall Family Care Plan must comply with the same guidelines.

The plan must include a projected budget for the identified services. If Family Care Coordination services are included in the Family Care Plan the budget must include projected costs for those services.

#### **Additional Notes**

- Services to be reimbursed by Medicaid must be determined by an appropriately licensed clinical professional to meet the definition of medical necessity.
- Services must either improve or ameliorate the existing condition.
- The care plan shall indicate the anticipated concentration and duration of service, the method for measuring progress towards obtaining the stated goals, and points for reassessment of service level, type and intensity.
- The Family Care Plan must indicate who (by name and title) is going to provide the services. If the specific individual provider is not yet identified this shall be indicated and this information provided to the CEDARR Family Center at the first opportunity.
- Coordination of efforts with other responsible organizations (e.g. E.I., LCC/CASSP, Special Education, other mental health agencies) must be defined and documented.

#### **4.6.3 Time Frame for CEDARR Family Center Action on Direct Service and Support Component of Family Care Plan**

It is anticipated that the proposed Direct Service and Support plan will be developed with full communication with the CEDARR Family Center and the family. The following guidelines are nonetheless established to ensure timely action.

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- The completed treatment proposal is forwarded to the CEDARR Family Center for review and action. The CEDARR Family Center actions can be:
    - Approval
    - Disapproval
    - Conditional Approval
    - Pend for further information or plan amendment
  - Additional information may be requested to enable a more informed review.
  - CEDARR Family Center action on the proposal must take place within 21 days of receipt. If no action is taken by that time, an appeal may be filed with the CEDARR Family Center. The CEDARR Family Center is required to notify the State within one business day of receipt of an appeal. If additional information or a plan modification is requested by the CEDARR Family Center, the clock stops at the point of the request; a new 21-day period commences upon receipt by the CEDARR Family Center of the additional information.
  - The maximum period for which approval may be granted for a plan is six months, although shorter time periods may frequently be deemed appropriate.

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## **V. CERTIFICATION STANDARDS**

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Section 4.0 above identified the scope of services and supports that must be provided by CEDARR Family Centers. Section 5.0, Certification Standards, identifies the standards against which applicants will be evaluated. Certification standards are identified in six core areas. These are:

- 5.1 Organizational Structure
- 5.2 Strength of Program Approach
- 5.3 Organization of Service Delivery System
- 5.4 Quality Assurance
- 5.5 Organizational Capability
- 5.6 Data Collection and Reporting

Within each core area, specific certification requirements, characteristics and performance expectations are indicated. Evaluation of applications will assess compliance with core requirements and the quality of the proposed program.

### **5.1 Organizational Structure**

#### **5.1.1 Incorporation**

The applicant for certification as a CEDARR Family Center must be legally incorporated. The certified entity shall serve as the accountable entity responsible for meeting all of the terms and conditions for a CEDARR Family Center. It is preferred, but not essential that the certified entity be a not for profit 501(c)(3) corporation. This would have enhance prospects for the receipt of grants.

The State recognizes that certification as a CEDARR Family Center requires a diverse set of capabilities. In many cases this means that the successful application will represent the coming together of several parties, each bringing a set of strengths and capabilities to the overall application and proposed program of care. This could come, for example, through formation of a new membership corporation, a joint venture, a formal partnership or an integrated series of executed contracts. Regardless of the form, a single legal entity will be certified with overall responsibility for performance.

The CEDARR Family Center is to be the single billing agent for all CEDARR Family Center services.

Applicants must clearly present the overall structure by which the services, requirements and programmatic goals of the CEDARR Family Center will be met. The corporate structure of the CEDARR Family Center must be clearly delineated. Governance must be identified; composition of the Board of Directors and any conditions for membership must be clear. Partnership and or contractually linked participants in the overall proposal must be identified

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along with their proposed role including families and or family support organizations including family members. The State requires disclosure of any linkages of participants with any other provider of CEDARR Family Center services and/or direct services. Potential conflicts of interest must be identified.

### **5.1.2 Well Integrated and Organized Management and Operating Structure**

The CEDARR Family Center will need to be able to function as an integrated system, assuring consistency and quality in performance across sites, assuring effective coordination of effort. Applicants must demonstrate:

- Clear roles and responsibilities for participating organizations if multiple organizations are involved; roles and responsibilities for participating departments or divisions should be clear if an applicant is a single entity. Copies of supporting documents (written executed agreements) must be included.
- Clear leadership. The applicant shall provide clear identification of who is accountable for CEDARR Family Center performance. This includes administration, CEDARR Family Center service delivery, the quality of family support and clinical services, and financial operations. A chart of organization must be provided.

### **5.1.3 Family Centeredness and Community Focus in Design of Organizational Structure**

Core dimensions of the CEDARR Family Center include family centeredness, use of informal networks and supports, and commitment to provision of care in the least restrictive and appropriate setting closest to home.

The CEDARR Family Center will demonstrate the ways in which these aspects of the CEDARR Program Initiative are addressed in the organizational structure of the CEDARR Family Center itself. Potential ways in which such concerns may be present are noted:

- Family participation on the Board of Directors; nature of participation.
- Formal family advisory committee for the CEDARR Family Center; for the local delivery sites.
- Intake assessment, care planning and care coordination conducted by trained Family Service Coordinators who, in addition to other qualifications, are themselves experienced consumers of services for children with special needs (i.e. family members).
- Evidence of linkages with, and leadership or participation of entities with strong local supports, history of engagement of informal networks.
- Support and endorsement of representative groups, parents, advocacy groups.

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- Organizational vision and/or mission statement endorsing key principles.

Presentation of any such organizational components should be clearly linked to their role in the activities of the CEDARR Family Center.

#### **5.1.4 Services Are Geographically Accessible To Families Throughout the State**

To be certified, the CEDARR Family Center must be soundly based in the local community of the children and families it serves. A CEDARR Family Center must demonstrate that it has statewide capacity to provide services to families in geographically accessible and local settings. This is particularly key for Basic Services and Supports. It is not required that specialized clinical services be available at the same locations as basic services, nor is it expected that specialized clinical services be locally available to the same extent as basic services and supports.

Applicants for certification as CEDARR Family Centers will identify the ways in which they propose to assure local access to services. Key is accommodation for the transportation difficulties that may be faced by families with limited resources. The applicant must:

- Identify the direct service sites proposed
- Indicate their location on a map
- Identify how this provides for statewide accessibility (e.g. proximity to populations, accessibility to public transportation).
- Provide assurance that all CEDARR Family Center Basic Services are available through the sites identified
- Sites for specialized clinical evaluation and treatment consultation

One approach to ensuring geographic accessibility may be through provision of mobile community based services. If this is proposed, the capability to provide such services should be identified and the conditions under which they would be provided on a mobile basis.

#### **5.1.5 Separation From Direct Service Provider**

The CEDARR Family Center plays the role of an independent evaluator and advisor for the family. It is also expected to help make referrals, review and approve direct service and supports, ensure receipt of services and periodically determine progress to date and, as appropriate re-evaluate and revise the Family Care Plan. In these regards the CEDARR Family Center is expected to both work closely with direct service providers and to maintain a level of independence.

The State generally believes that a CEDARR Family Center that is independent from direct service provision will be able to perform more effectively in its multiple roles than would a

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CEDARR Family Center more closely connected with direct services delivery. In evaluating applications for certification as a CEDARR Family Center, the State reserves the right to exercise discretion in assigning preference to respondents who are independent from direct service providers; failing this CEDARR Family Centers must demonstrate how they ensure an “arms length” relationship from direct service providers.

This distinction is important in:

- Assuring Family Choice/Avoiding Risk of Perception of Restricted Referrals

The CEDARR Family Center will play a key role for the family and for the State as an independent evaluator of need. The assessment and the treatment plan proposal must be focused on the strengths and needs of the child and family, with all available treatment options considered. Families need to be comfortable that they are informed as to the full range of treatment options available, that probing questions can be raised. Even the perception of a potential bias in treatment modalities or of conflict of interest is of consequence. Families have at times felt that the range of care services and supports has been too narrowly defined. There is concern that a CEDARR Family Center that is too closely tied to a particular direct treatment provider will (consciously or otherwise) systematically channel referrals to a particular treatment provider. Apart from deliberate steering, closeness of ties, greater familiarity with a program, and unspoken expectations could all influence referrals.

- Assuring Evaluations by Independent Experts

A critical dimension of the CEDARR Family Center role is to monitor provider performance and evaluate success in reaching objectives. Failure to separate the roles could create a conflict of interest for a CEDARR Family Center that is closely linked with direct treatment provision.

In cases where the applicant is not independent from direct service providers, applicants may propose arrangements whereby the “arms length” and independent nature of the CEDARR Family Center is assured. To the degree to which the State considers applications where there is not clear corporate separation from direct service providers, applicants will be evaluated based on the strength of these arrangements; future monitoring of certified entities will pay particular attention to this issue.

#### **5.1.6 Ability to Demonstrate a Positive Relationship with Provider Community**

CEDARR Family Centers must demonstrate strong knowledge of and the ability to work productively with direct service providers in local geographic areas and in areas of special need.

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### **5.1.7 State of the Art Clinical Expertise**

A central capacity for CEDARR Family Centers is the ability to serve as bona fide experts in the core areas of clinical expertise. In order to achieve the best health outcomes possible, the State intends that services to children with special health care needs be guided by the most advanced standards of care possible. Applicant organizations need to provide evidence that their proposal includes needed clinical expertise. CEDARR Family Center component areas of expertise include:

- Methods for accurate diagnosis and assessment of prognosis.
- Experience in strength based family centered practice.
- Design of individualized client/patient specific protocols of service based on current evidence-based research and clinical standards and protocols endorsed by the leading national experts in the area. Development of career plans with appropriate and measurable goals and objectives, service protocols to address such goals and objectives; determination of appropriate level of care, scope of services, frequency, intensity, duration, pharmaceutical regimen.
- Experience in service management and oversight, standards for prospective, concurrent and retrospective utilization review.

The applicant CEDARR Family Center will demonstrate clinical expertise in one or more areas. Clinical expertise will be evidenced in other areas of the proposal design and delivery of services. This standard (5.1.7) relates to the structural capabilities of the CEDARR Family Center and the resource basis for the clinical expertise. Key elements of this expertise can relate to:

- Affiliation with hospitals or other organizations with demonstrated professional expertise.
- Affiliation with university/research institution.
- Support and endorsement of representative groups, parents, advocacy groups.
- Qualifications of particular person(s) whose clinical expertise in this area is recognized in demonstrable ways by participation in and recognition by national subject committees, panels and/or other recognized bodies in the field.

### **5.1.8. Organizational Experience**

Applicants will be evaluated for the strength of their combined organizational experience in:

- Provision of basic services and family supports as outlined

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- Working with families and natural supports
  - Family Care Plan development and Family Care Coordination
  - Care plan design with review and oversight based on established clinical standards
  - Working with children with special health care needs
  - Recognition as strength based, family centered provider of services.

## **5.2 Strength of Program Approach**

### **5.2.1. Demonstrated Understanding of CEDARR Program Initiative and Role of CEDARR Family Center**

For certification, CEDARR Family Centers must (a) demonstrate clear understanding of the role of the CEDARR Family Center and (b) describe a service approach and philosophy consistent with the goals of the CEDARR Program Initiative.

Applicants' statement of understanding will articulate a clear statement of the services that will be provided and the area(s) of clinical specialty capacity required. Restating elements of the Certification Standards will not be sufficient.

### **5.2.2 Key Issues Impacting on Success**

Applicants must identify those things which they consider to be the key issues that will impact on the success of *their* efforts and how their program is designed to address those issues. These include concerns related to the particular health needs of children, needs of family, clinical resources, and others, but may encompass administrative or financial concerns as well.

### **5.2.3 Family Centered Program of Care**

CEDARR Family Centers must incorporate key components of family centered care into their philosophy, service program and operations. Applicants must demonstrate the manner in which important principles of family centered care are part of their program. Areas of attention might include:

- The degree and character of family involvement in program development, implementation, and evaluation
- The degree and character of family involvement in care planning
- Emphasis on family centered program outcomes
- Programs flexible enough to meet special and individual needs

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- Approaches to assuring families are encouraged to voice concerns and provide input
  - Combination of formal programs and informal networks and others

#### **5.2.4 Coordination With Other Parties**

CEDARR Family Centers are required to actively work to coordinate their efforts with other parties involved with the child and family.

Coordination with other parties and systems involved with the child and family is fundamental. The applicant must identify key issues that need to be addressed and specific approaches and strategies to be used. Systematic approaches should be identified for:

- State and local public agencies, including DCYF, DOE, DOH, MHRH and their related programs and entities (e.g., CASSP, Early Intervention, LEAs)
- RIte Care Health plans, commercial insurance, other
- Others, as appropriate to situation

#### **5.2.5 Place of Business/Dedicated Phone Line/Hours of Service**

CEDARR Family Centers must have an established place of business where children and families can access services. Sites must be physically accessible, identifiable and welcoming. The CEDARR Family Center must have its own identified phone line and identified reception. Twenty-four hour phone in capacity is required.

The CEDARR Family Center shall be open at least 35 hours and five days per week. Service hours should be scheduled in such a manner as to accommodate the schedules of working families (e.g. after work hours, evenings, Saturdays).

#### **5.2.6 Capacity to Provide Crisis Intervention Services, Twenty-four Hours Per Day, Seven Days Per Week**

CEDARR Family Centers must be available for crisis and urgent situations. The CEDARR Family Center shall provide 24-hour accessibility to qualified clinical personnel to children and families in need of immediate assistance in situations of imminent risk or urgent need. This access may be triaged through a 24-hour phone capacity with clearly defined protocols for contact with qualified on-call clinical staff. Service capacity must be as outlined in the Crisis Intervention sections of this document.

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### **5.2.7 Linguistic and Cultural Competency**

The CEDARR Family Center must demonstrate its ability to effectively communicate with persons for whom English is not their primary language. The CEDARR Family Center must demonstrate its ability to work effectively in multiple community and cultural settings with people of different racial, ethnic, class, language and religious backgrounds. The demographic composition of the staff of the CEDARR Family Center should be reflective of the communities served.

The CEDARR Family Center will demonstrate formal linkages with local community agencies that support and assist families from a variety of backgrounds. Areas of related concern that should be addressed include identification of the languages in which services will be available by type of service (e.g. reception, family intake, family care planning, clinical services); this should include the degree to which this is the same at all sites of service. Materials descriptive of the CEDARR Family Center and the service program must be available in different languages and at literacy levels accessible to the widest audience. Examples of such materials might be included in an application. Services and supports must be equally available to families regardless of the complexity or nature of the child's and family's needs, culture, geographic location or spiritual beliefs.

### **5.3 Organization of Service Delivery System**

CEDARR Family Centers are required to provide the full range of services and supports that are described in this document. They are required to maintain multiple service sites throughout the State to ensure community based access. The range of required services includes a combination of basic services and supports and specialized clinical services. It is required that this overall service delivery system be integrated and managed in a way which provides for consistency across settings, quality of care, and clear lines of accountability for performance. Applicants are also encouraged to work creatively in establishing partnerships that can combine and leverage the unique strengths of different entities and programs.

This section of the Certification Standards identifies areas of the organization of the delivery system, which must be effectively addressed and described in order to be certified. This section of the Certification Standards also stipulates certain requirements regarding staff qualifications required for the performance of certain functions.

It is in the design and development of the organization of the service system that the underlying philosophy and approach of the CEDARR Family Center is fully articulated. This includes such dimensions as the manner in which principles of family centeredness are embodied in the organizational structure, nature of commitment to provision of high quality clinical services, and the standards of accountability for performance.

#### **5.3.1 Chart of Organization**

The applicant must demonstrate a sound organizational approach to ensure the provision of effective, timely, high quality CEDARR Family Center services. This is partly represented in

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the staffing strategy employed to organize the work. This structure must be consistent with the underlying clinical approach and philosophy as well as clinical protocols.

For the full scope of services applicants must provide a clear delineation of the staff roles, reporting relationships and supervision. Job titles must be identified. A defined chart of organization must be provided and maintained on a current basis as personnel changes and relationships are adjusted. The chart of organization must indicate both the job titles and the specific individuals who fill identified positions.

### **5.3.2 Service Team Roles, Practice Guidelines and Scope of Practice**

A CEDARR Family Center must maintain satisfactory written practice guidelines along with identification of how adherence to such guidelines is systematically monitored. Protocols will include clear delineation of the role and scope of practice of each position within the service provision team. The respective roles of licensed professional and non-professional personnel need to be clearly defined. Clear description of the role of each member is needed in such areas as:

- Roles in the provision of each of the CEDARR Family Center Services and Supports
- Supervision, scope of practice
- The ways in which clinical supervision is effected, ratio of supervisors time to treatment team staff time
- Staff evaluation
- Family Care Plan design
- Plan modification
- Care coordination with other care providers

Protocols should identify CEDARR Family Center standards regarding team meetings, case conferences, team participants, periodic assessments, and plan revision as appropriate. Protocols should identify guidelines regarding coordination with other parties involved with the child and family.

The ways in which service provision teams are organized will vary by CEDARR Family Center and organization of the service program. For illustrative purposes, potential care teams might include:

Family Service Coordinator—Responsible for initial contact with child and family, coordination of IFA, provision of basic supports, convenes Peer Family Support group sessions, assists in Family Care Plan development, Family Care Coordination. Is the guardian or care giver of a

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child with special health care needs, who has received services through the State or local system of care, treatment and special education for children with disabilities. Works under the direct supervision of the licensed clinician.

**Licensed Clinician**—Responsible for completion of IFA, Family Care Plan, supervision of Family Service Coordinator, Family Care Plan development, Family Care Coordination. Must be licensed at the independent practice level as a licensed clinician (e.g. Licensed Clinical Social Worker, Nurse Practitioner, Master level counselor, Psychologist, as appropriate to the specialty area of the CEDARR Family Center). Family Care Coordination includes referral coordination. Staff knowledge of, and relationship with, the statewide and regional provider community is essential.

**Expert Clinician Consultant**—Provides comprehensive clinical evaluation and assessment, assists in development of Family Care Plan, conducts re-evaluation, treatment consultation, participates in case review conferences. Must be a licensed clinical professional at the highest degree recognized in the field (e.g. M.D., Ph.D.).

Detailed job descriptions must be developed for each position. Personnel providing CEDARR Family Center Services must meet all applicable State requirements. All CEDARR Family Center personnel will be required to complete a training program approved by the State. An applicant organization must have a process in place by which it assures the competence of service team members. Position job descriptions will address such areas as:

- Reporting relationship
- Functional tasks, performance expectations
- Required skills, training, experience. Specialized knowledge of, experience with, area of special health need, public service systems, community resources, care coordination might be indicated. Requirements might specify education and degree requirements, specialized training, specific requirements pertinent to current competence to perform role
- Licensure or certification requirements
- Orientation and/or in service training requirements prior to provision of services
- Successfully passed a criminal record clearance
- Nature of engagement (employee of specified entity, contracted consultant, other)

### **5.3.3 Service Delivery Practice Guidelines and Protocols**

For each CEDARR Family Center service or support delivered, the CEDARR Family Center must maintain sound written and approved clinical practice guidelines, with identification of how adherence to such guidelines is systematically maintained and monitored. The protocols represent the agency's statements of best practice standards and should be subject to periodic review and updating. These should include:

- Statement of approach to provision of this service, defined objectives
- Expected role of family, staff, other parties
- Time lines for performance
- Identification of any standard tools used (e.g. for Initial Family Assessment)
- Foundations in, or commitment to evidence based practice
- Scope of practice limitations for individual staff positions

### **5.3.4 Data Collection and Outcome Measures**

It is intended that the work of the CEDARR Family Center be a data driven system. The successful applicant will demonstrate ability to continually evaluate and analyze all data on the individual child and family, including interpreting, integrating and communicating data to and from professionals, children and their families. Cooperation with the State in data system design and compliance is essential.

## **5.4 Quality Assurance**

### **5.4.1 Quality Assurance Plan**

The program is required to have policies and procedures and demonstrated activities for quality review and improvement acceptable to the State, including a current Quality Assurance plan. Components might include:

- Regular case conferences
- Care process improvement strategies
- Audit of client records for completeness and accuracy
- Degree to which all of the services identified in the treatment plan are actually provided
- Methods of evaluating staff performance
- • Outcome analysis

- Degree of coordination with other systems, coordination of plans
- Identification of internal performance standards in such area as
  - Phone abandonment rate
  - Timeliness of appointments
  - Caseload standards for personnel; percent compliance

The agency's Quality Assurance plan shall include time tables for plan objectives and systematic review by the governing board of the agency.

#### **5.4.2 Recordkeeping**

The CEDARR Family Center shall maintain a complete confidential case record for each child and family. The record shall include but is not limited to:

- Initial Family Contact intake form
- Date of initial contact with CEDARR Family Center
- All assessment related materials, including delineation of problems and strengths, involvement of key parties, preliminary service plan
- Family Care Plan, including goals, objectives, goals and objectives attainment summary, treatment modalities, service scope and duration, performing provider (by name), time frame
- CEDARR Family Center contacts and plan approvals
- Progress notes, notation of involvement with family, others (e.g. Early Intervention, Special Education, CASSP)
- Clinical specialty evaluation recommendation
- Case conference summaries
- Recommendations for treatment plan modification, discharge, continuance.
- Ongoing progress reports

### **5.4.3 Confidentiality**

The agency must have written policies and procedures for maintaining the confidentiality of data, including client records. The agency must have provision for sharing information about the treatment with the direct treatment providers, the primary care provider and others as appropriate.

### **5.4.4 Staff Credentialing**

The agency shall have an identified credentialing process established to ensure that staff meet all requirements for their respective positions. Current records shall be maintained to document compliance.

### **5.4.5 Continuing Education**

The CEDARR Family Center is required to ensure that service staff maintain and improve upon critical knowledge and skills needed to provide high quality services. Participation in the State CEDARR approved multi-disciplinary training will be required. This training will include but not be limited to “cross training” regarding medical issues, developments in current research, understanding of family centered practice, issues in behavioral health, special education and child welfare.

### **5.4.6 Environment of Care**

It is critical that the agency have an established approach to ensuring safety in the care environment for both the client and for staff (e.g. protocols for identification and monitoring of safety risks, guidance to staff and to families for how to identify and deal with difficult and potentially dangerous situations).

### **5.4.7 Grievance and Appeals, Family Satisfaction**

The CEDARR Family Center shall have an established approach to ensuring child and family rights. A family friendly, non-threatening, well publicized grievance and appeals process shall be established. Related policies, procedures, and materials are to be provided to families at the onset of involvement and at least annually thereafter. The family’s role in resolution should be clearly developed. Such materials shall advise the family of grievance and appeal procedures within the CEDARR Family Center, the State and the legal system.

The CEDARR Family Center shall have established policies, procedures and related records to ensure focus on customer service, solicitation of family input, documentation and response to complaints, and prompt complaint resolution.

The CEDARR Family Center should have an established State approved method for assessing family satisfaction at least annually.

## **5.5 Organizational Capability**

### **5.5.1 Administrative and Financial Systems**

The CEDARR Family Center must have sufficient capability to carry out the various operational functions necessary to oversee and support the program. Related areas include capacity to manage ongoing operations, to coordinate effectively across multiple sites and to maintain positive partnerships with the various involved entities or programs. Applicants must demonstrate an effective approach to program management, identifying key issues which are addressed in the applicant's plan.

Applicants must further demonstrate a sound approach to financial management. This is particularly critical where the CEDARR Family Center involves the joint efforts of more than one party. The applicant must provide a description of the core financial team and support system, including such areas as:

- Demonstrating capacity for timely billing for services and describing arrangements for internal calculation of services generated by site and by type, for revenue distribution to participating parties and for tracking payments received against claims
- Methods for determining future cash requirements and plans for ensuring adequate cash flow
- Risk management arrangements, with specific attention to general liability, professional liability, and directors and officers liability
- Policies, procedures and experience in third party liability and coordination of benefits in relation to Medicaid

### **5.5.2 Business Plan Projections for CEDARR Family Center**

Applicants must provide a sound business plan, including plans for development and a projected monthly revenue and expense statement for the first twelve months of operation with appropriate line item notes to identify assumptions (e.g. number of persons served, services to be provided, associated revenues and expenses). The plan should also identify the ways in which initial expenses leading to operations will be managed.

### **5.5.3 Independent Audit**

The applicant must provide a copy of its most recent audit.

## **5.6 Data Collection And Reporting**

A primary responsibility of a CEDARR Family Center is to provide information to both the family and to the State. On a regular and continuing basis, the CEDARR Family Center will collect and assess progress updates from all Direct Service and Support providers, will collect and analyze both utilization and outcome data, and will incorporate this information in the re-evaluation of the Family Care Plan, as necessary. On an aggregate basis, the CEDARR Family Center will provide the State with reports on a quarterly basis describing activity, service utilization, and outcomes for all children and families having a relationship with the Center. On not less than an annual basis, the Center will provide the State with an assessment of each Direct Service and Support provider to whom a referral has been made within the previous twelve months, describing the number of referrals, apparent programmatic strengths and weaknesses of each, as well as a comparative analysis of outcomes achieved.

- The application shall describe in detail the proposed data collection and reporting plan (hardware, software, connectivity to State computer systems, data configuration and strategy for collection). The State reserves the right to negotiate the details of this plan with successful applicants.

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**APPENDIX I:**  
**REIMBURSEMENT FOR SERVICES**

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## **APPENDIX I: REIMBURSEMENT FOR SERVICES**

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“Reimbursement for Services provided by CEDARR Family Center” will be available on or about June 2, 2000

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**APPENDIX II:**  
**ESTIMATES OF NUMBER OF MEDICAID ELIGIBLE CHILDREN**  
**WITH POTENTIAL INTEREST IN**  
**ACCESSING SERVICES OF A CEDARR FAMILY CENTER**

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## **APPENDIX II**

### **ESTIMATES OF NUMBER OF MEDICAID ELIGIBLE CHILDREN WITH POTENTIAL INTEREST IN ACCESSING SERVICES OF A CEDARR FAMILY CENTER**

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#### **1. Background**

Appendix II provides an estimate of the number of Medicaid eligible children with special health care needs who might opt to utilize a CEDARR Family Center. DHS' intent herein is to provide information that might assist potential applicants in making informed judgments as to the number of children and families who might access a CEDARR Family Center and the volume of services that might be sought.

The basis for this estimate is described in the text. Potential applicants for CEDARR Family Center certification should review this in conjunction with, and in consideration of, any other related information that may be known to the applicant. DHS does not know how many people will choose to access the CEDARR Family Center services. Many families currently receiving services through other means may be fully satisfied with those services and will continue those relationships. Definitions of special health need can vary widely. Unlike many other programs focusing on special needs there are no specific eligibility requirements related to type, degree, or severity of health need. The family of a Medicaid eligible child is free to make the decision to access a CEDARR Family Center based on individual judgment and circumstances.

#### **2. Children with Special Health Care Needs**

For a variety of reasons it can be of value to derive accurate estimates of the number of children with special health care needs present in a population. The methods for doing so can vary substantially. A core consideration is the indicator used to determine whether special need exists or not and the source of data for indicator information. Studies seeking to determine the prevalence of special need may be based on such criteria as (a) presence of certain diagnoses for specific physical, developmental, or behavioral health conditions), (b) presence of specified functional limitations or (c) identification of persons who utilized certain categories or types of service. Any of these approaches may be used in a research based empirical analysis of the prevalence of special health care needs among children. There are many methodological and philosophical issues to be grappled with in such an undertaking.

The approach taken here is far simpler, drawing on the work of others to make reasonable estimates of prevalence among Medicaid eligible children. The starting point is the broadly stated definition for special health care need used by the Federal Maternal and Child Health Bureau (MCHB). The Bureau uses the following definition:

Those children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.

This definition is not categorical in nature and is consistent with the spirit and intent of the CEDARR initiative. Based on this definition the Maternal and Child Health Bureau has variously estimated that in the general population, between 15% and 20% of children have a special health care need. In combination with known characteristics of Medicaid eligible children, this estimate is used as the foundation for the numbers developed here.

For purposes of this analysis Medicaid eligible children fall into three primary groupings which are presumed to have distinct profiles of special health need. The first includes those RIt Care enrolled children who are Medicaid eligible predominantly based on family income. While recognizing that some adjustments may be appropriate based on the relationship between income and health status, this group is assumed to largely mirror the general population of children reported on by the Maternal and Child Health Bureau. The second group includes those children who are on fee-for-service Medicaid based on SSI (including Katie Beckett). For these children, Medicaid eligibility is based on the presence of a special health care need. A study conducted of this group in June 1998 by MCH Evaluation Inc. in conjunction with the Department of Human Services provides a fairly detailed profile of this group. That study provides the basis for making estimates for this group regarding the distribution of children by type of special health care need. The third group includes those children who are on fee-for-service Medicaid and who are Medicaid eligible due to their status with DCYF. This group is assumed to be at risk for a higher incidence of behavioral health related needs.

### 3. Population Estimates

Table 1 presents a estimate of children with special health care needs based on Medicaid eligibility group. Notes on the basis for estimations are provided.

<b>Table 1: Estimate of Total Population of Children with Special Health Care Needs Who May Access CEDARR System of Care</b>			
RIt Care	FFS - SSI	FFS - DCYF	Total
3,234	5,334	1,339	9,904

### 3.1 Basis for Estimates

#### 3.1.1 RIt Care

Using the definition cited above, MCHB estimates that between 15% and 20% of the general population of children have a special health care need. Applying the more conservative 15% figure to the RIt Care population (approximately 64,677 children) we get a population of 9,702.

On the assumption that 15% is too large of a number for the level of need anticipated by CEDARR, a 5% estimation factor is used. This yields an estimate of 3,234 children.

### 3.1.2 Fee for Service Medicaid

The SSI age 0 - 21 population (including Katie Beckett) includes approximately 5,334 children. All are assumed to have special health care needs.

The DCYF population is approximately 4,511. These children are assumed to have a higher than average risk profile for special need, particularly in the area of behavioral health. It is estimated here that up to 25% of these children will have special health care needs.

### 3.2 Estimates are for a particular period, not annualized totals

In each case, the total population used (SSI - 5,334; DCYF - 4,511; RItE Care - 64,677) is taken as an average eligible population per group during the last quarter of calendar 1999. The annual total of unduplicated individuals would be larger. The pool of potential users of services for any particular point in time, however, is based on current eligibles. All estimates are on a statewide basis.

### 4.0 Types of Health Needs, Estimates of Distribution by Diagnostic Grouping

The next step taken was to develop estimates of the population by type of health need. Table 2 presents related estimates.

<b>Table 2: Estimates of Distribution of Children with Special Health Care Needs by Diagnostic Grouping</b>				
<b>Type of Special Health Care Need</b>	<b>SSI</b>	<b>DCYF - Foster</b>	<b>RItE Care</b>	<b>Total</b>
.	N = 5,334	N = 4,511	N = 64,677	
Physical disability (primary only)	693			
<i>Dual diagnosis with physical primary disability as primary</i> Physical (primary), developmental (secondary)	879			
Physical (primary), Behavioral)	288			
Physical (primary), Developmental, Behavioral	22			

<b>Table 2: Estimates of Distribution of Children with Special Health Care Needs by Diagnostic Grouping</b>				
<b>Type of Special Health Care Need</b>	<b>SSI</b>	<b>DCYF - Foster</b>	<b>Rite Care</b>	<b>Total</b>
.	N = 5,334	N = 4,511	N = 64,677	
TOTAL, <i>Physical Disability</i>	1,882	87	1,078	3,047
Behavioral Health (primary only)	623			
<i>Dual diagnosis with <u>behavioral health as primary</u></i> Behavioral Health (primary), physical (secondary)	229			
Behavioral health (primary), developmental (secondary)	479			
Behavioral (Primary), physical and developmental (secondary)	128			
Total, <i>Behavioral Health</i>	1,459	993	1,078	3,530
Developmental Disability/MR (primary only)	1,135			
<i>Dual diagnosis with <u>developmental disability as primary</u></i> Developmental Disability/MR (primary), physical (secondary)	603			
Developmental disability (primary), behavioral (secondary)	74			
Developmental disability (primary), physical and behavioral (secondary)	181			
Total, <i>Developmental Disability</i>	1,993	256	1,078	3,327
TOTAL	5,334	1,336	3,234	9,904

Below are notes on the basis for the estimates provided in Table 2:

#### **4.1. SSI Eligible Children (including Katie Beckett)**

These estimates are based on the June 1998 report on SSI eligible children prepared by MCH Evaluation. A survey was conducted with 257 families. The classification of disability is based on the caregiver's report of the primary disabling condition.

#### 4.1.1 Dual Diagnoses

In fifty-four percent (54%) of SSI cases, an additional disability was identified in the June 1998 survey. The breakdown of those cases is presented by the primary disabling condition that was identified by the care giver.

#### 4.1.2 Classifications of Conditions by Diagnostic Grouping

The MCH Evaluation Report uses the following classification schema:

CATEGORY	Types of Disability Reported
Physical	Brain tumor, neuroblastoma, lymphoma, leukemia, Sotos syndrome, metabolic disorder, Wilson's disease, Cystic Fibrosis, Sickle cell anemia, hemophilia, hydrocephalus, hemiparesis, cerebral palsy, paralysis, epilepsy, muscular dystrophy, blindness, deafness, asthma, tracheomalasia, short gut, kidney defect, lupus, scoliosis, gastroschisis, epidermolysis bullosa, Prader Willi syndrome, prematurity, seizure disorder, traumatic brain injury, fracture, near drowning
Behavioral	Serious emotional or behavioral disorder, schizophrenia, manic depression, psychoses, anxiety, post traumatic stress, attention deficit disorder, attention deficit hyperactivity disorder
Developmental	Learning disability, pervasive developmental delay, mental retardation, autism,. Down syndrome, speech disorder

#### 4.2 DCYF Involved Fee-For-Service Children

The numbers presented here are rough estimates and do not derive from any specific study as was used for the SSI eligible children.

- The number of children with physical disabilities is estimated at 2% of the population. This number is set somewhat low on the premise that children with severe physical disabilities who are involved with DCYF are generally assumed to be in the SSI category.
- Behavioral Health - The circumstances of their placement in DCYF custody make children particularly vulnerable in the area of behavioral health. Medimetrix' 1997 analysis of claims data indicated that 17% of the DCYF eligible children received behavioral health services in the six month period examined. A more recent DHS staff analysis of persons using mental health/substance abuse services through the fee-for-service system (SSI and DCYF) during the period January, 1998 - March, 1999 showed 26% of eligibles used services during any given three month period. For the purpose of the numbers presented here, a mid-range estimation factor of 22% is applied to the 4,511 DCYF eligibles.

- Developmental Disabilities - The Medimetrix report indicates that in a six month period 17% of eligibles received Early Intervention, Head Start, LEA or Targeted case management services. It is assumed here that two-thirds of those cases are duplicative with other categories noted above (physical, behavioral). On this basis roughly one-third of the 17% or 5.7% of the children using the services indicated above are assumed to have a developmental disability.

### **4.3 RItE Care Estimates**

The Maternal and Child Health Bureau has estimated that between 15% and 20% of children in the general population have a special health care need. For this analysis a smaller percent is estimated to have serious or severe special health care needs. A figure of 5% is used to approximate the number of persons with serious or severe special health care needs, those who might most benefit from the services provided through the CEDARR Program Initiative. Based on income status RItE Care eligibles could generally be assumed to have a somewhat less favorable health profile than the general population, justifying use of a higher figure. The RItE Care population will also include some persons who have spent down “excess income” on medical expenses. On the other hand, many of those persons with the highest level of need will be represented within the SSI and DCYF populations rather than in the RItE Care population. In this regard the 5% figure is used as the estimation factor for the RItE Care population.

In making estimates of the number of persons with physical, behavioral and developmental disabilities, the population is divided into equal thirds.

### **5.0 Concluding Remarks**

There is much that remains to be learned regarding the special health care needs of children and families in Rhode Island. The CEDARR Program Initiative will play a critical role in both improving care and in better understanding the extent and breadth of needs. These population estimates are presented as reasonable approximations of the size of the population, based on special health need, that *may* opt to utilize CEDARR Family Centers and related services. What proportion would actually do so remains to be seen. The specific bases for the estimates are provided so that readers may make independent judgments as to their value and level of accuracy. They may be reviewed in the context of other related efforts. A source of particular relevance might be the recently released 2000 Rhode island KIDS COUNT Factbook. Included in that report is a summary of the children who are enrolled in special education.. Table 26 in that report identifies the number of children and youth in special education, by primary disability and by town, ages 3 - 22.

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**APPENDIX III:  
APPLICATION GUIDE**

**For**

**Certification as a CEDARR Family Center**

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## **APPENDIX III: APPLICATION GUIDE**

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### **GENERAL INFORMATION**

#### **1. Overview**

This application guide is provided as a part of the Certification Standards for CEDARR Family Centers (Appendix III) and provides information and instructions regarding the submission process and the review of applications. It is intended to direct applicants in the organization and presentation of application materials.

#### **2. Application Submission and Review**

The initial date of issuance of certification standards for CEDARR Family Centers is May 25, 2000. Completed applications will be accepted for review commencing on July 21, 2000. The State will convene a CEDARR Family Center Application Review Committee to evaluate applications and submit recommendations on certification to the Associate Director, Division of Health Care Quality, Financing and Purchasing, Department of Human Services. Applications for certification as a CEDARR Family Center may be submitted any time from July 21, 2000 onward. There is no specific limit on the number of entities which can be certified as a CEDARR Family Center. Following the initial review process Application Review Committees will be convened from time to time as needed to review submitted applications. Applications submitted by the close of business July 28, 2000 will be included in the initial review process.

Beginning on June 2, 2000 the State will conduct Technical Assistance and Informational Workshops on the CEDARR Family Center certification standards and review process. Based on continued participant interest, these meetings will be held on a weekly basis up until the week in which the State will first accept final applications.

In the course of these workshops questions may be raised with respect to certain aspects of these Certification Standards which the State will choose to respond to in writing. If an applicant requires specific clarification regarding aspects of these Certification Standards a written request to that effect should be submitted and a written response will be provided. All written responses will be issued as CEDARR Family Center Memoranda. These Memoranda will represent formal extensions of, and amendments to, these CEDARR Family Center Certification Standards. The Certification Application Guide may also be amended to accommodate these changes or to provide more specific guidance on required materials.

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In order to ensure that potential applicants are kept fully informed of any such amendments it is required that applicants submit a Letter of Interest at least thirty (30) days prior to submission of a final application.

Letters of Interest and Applications for Certification are to be submitted to:

Sharon Kernan, R.N., M.P.H..  
Assistant Administrator, Community & Planning Services  
Center for Child and Family Health  
Department of Human Services  
600 New London Avenue  
Cranston, Rhode Island 02920  
Phone: (401) 462-3392

Applicants for certification must submit an original and ten (10) copies of all materials.

### **3. Compliance Review**

Prior to technical review, submitted applications will be reviewed for completeness and for compliance with core expectations. Incomplete applications will be returned without further review. Completed applications may be re-submitted at a later date.

### **4. Application Scoring**

The Certification Standards for CEDARR Family Centers provide an overall description of the CEDARR Initiative and outline the terms and conditions that will govern operation and oversight of CEDARR Family Centers. Section V of this Certification Standards document identifies the specific standards against which applicants will be evaluated. These standards are grouped in six core areas or *application components*. These application components are listed below along with the relative weighting in the overall scoring.

Application Component		Weighting
1.	Organizational Structure	35%
2.	Strength of Program Approach	20%
3.	Organization of Service Delivery System	15%
4.	Quality Assurance	15%
5.	Organizational Capability	5%
6.	Data Collection and Organization	10%

For each of these six areas the Certification Standards document identifies specific certification requirements or individual standards. Each individual standard is in turn weighted for its contribution to overall scoring within the respective application component.

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Level of proposal compliance with each standard will be scored individually. Based on review of applications, each standard will be scored as follows:

Score 1 <i>Inadequate compliance.</i>	The organization fails to meet the expectations of the standard.
Score 2 <i>Limited Compliance.</i>	The organization meets few expectations of the standard.
Score 3 <i>Partial Compliance.</i>	The organization meets some expectations of the standard.
Score 4 <i>Significant Compliance.</i>	The organization meets most of the expectations of the standard and its approach demonstrates sufficient understanding of, and commitment to, program expectations.
Score 5 <i>Substantial Compliance.</i>	The organization consistently meets or exceeds all major expectations of the standard and demonstrates particular strength in its approach.

Certification applications will be independently reviewed by assigned members of the review team. The review team may choose to conduct a site visit and readiness review in order to complete its work. The final score for each standard will be the average of the scores assigned by the review team members. A threshold total score for all areas will be established as the basis for recommendation for provisional certification. Certification will not be recommended for an applicant scoring below three on any individual standard. For certain standards a higher minimal threshold may be established.

A key element in review is the applicant's readiness to begin services. Applicants are expected to demonstrate their ability to begin service delivery not later than thirty (30) days from formal notification of certification.

## **APPLICATION GUIDE FOR CERTIFICATION AS A CEDARR FAMILY CENTER**

*Instructions:* Certification as a CEDARR Family Center is achieved through State approval of this written application and on-site review (optional based on State discretion). This application guide identifies the information required to conduct the certification review. All sections should be completed fully so as to sufficiently describe the applicant's approach to meeting the certification standards. Additional materials may be attached as appropriate.

### **1. Letter of Transmittal**

Each application must include a letter of transmittal signed by an owner, officer or authorized agent of the applicant. The letter shall identify that in submitting the application it is understood that the applicant agrees to comply with the program requirements and certification standards as

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issued and amended from time to time. DHS reserves the right to amend these requirements with reasonable notice to participating providers. The applicant further understands that as a provider within the Medicaid program it is obligated to comply with all state and federal rules and regulations that apply to Medicaid providers more generally.

## **2. Executive Summary**

The Executive Summary is intended to highlight the contents of the application and provide the review team with a broad understanding of the applicant's structure and approach.

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### 3. Cover Sheet

Name of Corporation Submitting Application: \_\_\_\_\_

Name and Title of Person Authorized to Conduct Business on Behalf of Corporation:

Name: \_\_\_\_\_

Title : \_\_\_\_\_

Contact Person for Questions on Application: \_\_\_\_\_

Address (street): \_\_\_\_\_

City or Town: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Federal employee identification number: \_\_\_\_\_

Medicaid Provider Number (if applicable): \_\_\_\_\_

Date of Application Submission: \_\_\_\_\_

### 4. Background on Applicant

To orient the reviewer and facilitate understanding of the materials that follow, please provide a brief introduction to the application. This might, for example, describe some of the background considerations leading to submission of the application and/or the structure of the organizational partnerships and affiliations represented. Formal affiliations should be identified.

### 5. Body of Application

The main body of the application should be organized as delineated below. This sequencing corresponds with that contained in Section V , *Certification Standards for CEDARR Family Centers*. Applicants should reference Section V in particular and the *Certification Standards* more generally for further guidance in addressing individual items. Any changes, amendments or clarifications to the *Certification Standards* will be distributed to all entities which have submitted a formal Letter of Interest as outlined above.

#### 5.1 Organizational Structure

- 5.1.1 Incorporation
- 5.1.2 Well Integrated and Organized Management and Operating Structure
- 5.1.3 Family Centeredness and Community Focus in Design of Organizational Structure
- 5.1.4 Services are Geographically Accessible to Families Throughout the State
- 5.1.5 Separation From Direct Service Provider

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- 5.1.6 Ability to Demonstrate a Positive Relationship with Provider Community
  - 5.1.7 State of the Art Clinical Expertise
  - 5.1.8 Organizational Experience

## **5.2 Strength of Program Approach**

- 5.2.1 Demonstrated Understanding of CEDARR Initiative and Role of CEDARR Family Center
- 5.2.2 Key Issues Impacting on Success
- 5.2.3 Family Centered Program of Care
- 5.2.4 Coordination with Other Parties
- 5.2.5 Place of Business/Dedicated Phone Line/Hours of Service
- 5.2.6 Capacity to Provide Crisis Intervention Services, twenty-four hours/day, seven days per week
- 5.2.7 Linguistic and Cultural Competency

## **5.3 Organization of Service Delivery System**

- 5.3.1 Chart of Organization
- 5.3.2 Service Team Roles, Practice Guidelines and Scope of Practice
- 5.3.3 Service Delivery Practice Guidelines and Protocols
- 5.3.4 Data Collection and Outcome Measures

## **5.4 Quality Assurance**

- 5.4.1 Quality Assurance Plan
- 5.4.2 Record keeping
- 5.4.3 Confidentiality
- 5.4.4 Staff Credentialing
- 5.4.5 Continuing Education
- 5.4.6 Environment of Care
- 5.4.7 Grievance and Appeals, Family Satisfaction

## **5.5 Organizational Capability**

- 5.5.1 Administrative and Financial Systems
- 5.5.2 Business Plan Projections for CEDARR Family Center
- 5.5.3 Independent Audit

## **5.6 Data Collection and Reporting**

## **6. Readiness**

It is expected that certification applications submitted to the State will describe a structure and approach to service delivery which is substantially complete at the time of submission. Applicants will be expected to be able to provide services in accordance with CEDARR Family Center requirements not later than thirty (30) days following notification of the approval of their application. Part of the certification review involves assessment of readiness. Information must be provided that will enable the State to make informed assessments regarding readiness. The State recognizes that in some cases certain aspects of the application may describe intentions of

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the CEDARR Family Center applicant rather than capacity actually in place on the date of submission of the application. The applicant should clearly identify the points at which the application describes currently existing versus planned activities and capacity. This section of the application should provide specific appropriate detail as to any outstanding tasks and associated time lines for completion. Additionally, it is anticipated that applications may represent the combined efforts of more than one entity. Application submissions should include copies of all executed contracts and/or affiliation and partnership agreements which detail respective responsibilities, authorities and related financial arrangements. This shall include pertinent incorporation documents or filings.

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**APPENDIX IV:  
GLOSSARY OF TERMS**

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## **APPENDIX IV: Glossary of Terms**

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### **Arms Length**

A demonstrated functional separation between the CEDARR Family Center and Direct Service Providers. An arms length relationship will provide demonstrable assurance to both families and the State that evaluations and referrals for service are family centered and independent.

### **CASSP**

CASSP (Child and Adolescent Services System Program) is a network of eight Local Coordinating Counsels throughout Rhode Island that bring together families and community agencies to plan and provide services that help families keep their children at home. This program is administered by the Department of Children, Youth and Families.

### **CEDARR**

Comprehensive, Evaluation, Diagnosis, Assessment, Referral and Re-Evaluation.

### **CEDARR Family Center Certification Application**

Entities seeking to be certified by the State as a CEDARR Family Center must submit this application for review, evaluation and formal action. Any qualified organization may apply for certification as a CEDARR Family Center.

### **CEDARR Eligibility for CEDARR Services and Supports**

All children with special health care needs and their families are eligible to access services and/or supports through certified CEDARR Family Centers. The State will pay for such services provided to Medicaid eligible beneficiaries.

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## **Glossary of Terms (Continued)**

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### **Certified CEDARR Direct**

**Services Provider** An entity certified by the State to provide specific CEDARR Initiative services and/or supports.

### **Certified CEDARR Family Center**

An entity that has been formally certified by the State as a CEDARR Family Center qualified to provide comprehensive evaluation, diagnosis, assessment, referral and re-evaluation services as well as related assistance and coordination for children with special health care needs and their families.

### **CEDARR Initiative**

A State sponsored initiative to enhance services for children with special health needs and their families. This comprehensive initiative addresses core issues in policy, access, quality, delivery system structure, inter-agency coordination and funding.

### **Certification**

The process through which the State formally identifies an entity as eligible to receive payment for provision certain Medicaid reimbursable services.

### **Children with Special Health Care Needs**

Those children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.

### **Comprehensive**

The inclusion of a broad range of health, educational, social, and related services in delivering care to a child.

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## Glossary of Terms (Continued)

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### **Cultural Competence**

Knowledge, sensitivity and respectful policy, practice and philosophy responsive to the specific cultural orientation of diverse populations.

### **EI**

Early Intervention is a statewide early childhood program responsible for the planning and provision of services relating to eligible children birth to three years of age with established risk or developmental delays as defined in Part C of the Individuals with Disabilities Act (IDEA). This is a Federal program administered in Rhode Island by the Department of Health.

### **EPSDT**

EPSDT stands for Early Periodic Screening, Diagnosis and Treatment. EPSDT refers to a mandate that Medicaid programs provide a broad spectrum of services to children to meet their health needs. States are required to screen eligible children, diagnose conditions found through the screen and then furnish appropriate medically necessary treatment to correct or ameliorate conditions discovered through the screening process. In this respect EPSDT encompasses all services provided to children under Medicaid. EPSDT is not a separate program. Non-traditional services which require prior approval by DHS, have sometimes been informally referred to as “EPSDT prescription services.”

### **Family Care Plan**

A comprehensive care plan developed by the CEDARR Family Center in collaboration with the family and other involved persons and entities. This comprehensive plan should incorporate any and all other plans (e.g. IEP, IFSP), by pro-actively including all stakeholders in the child’s care in the planning process, including the family and those direct care providers who will implement the plan.

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## Glossary of Terms (Continued)

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### **Family Centered**

Care that recognizes and respects the pivotal role of the family in the lives of children. It supports families in their natural care-giving roles, promotes typical patterns of living, and ensures family collaboration and choice in the planning and provision of services and supports to the child and family.

### **Family Needs**

The needs of families for health services or supports related to the demands of the special health care needs of their children, specifically those necessary to allow the family to appropriately care for their child with special health care needs.

### **Geographically Available**

Care that is accessible to all children regardless of their place of residence.

### **IEP**

Individual Educational Plan developed for children by the LEA Special Education Directors and professionals at the local schools to assess, plan and provide necessary services and supports for children with special education

### **IFSP**

An Individualized Family Service Plan developed as part of the EI program which is developed after a child is accurately identified, located, evaluated and found eligible. This plan is developed to accurately reflect an at-risk child's needs and the individualized EI service plan for the child and their family.

### **Individualized**

Care that reflects the unique physical, developmental, emotional, social, educational, and cultural needs of the individual within the context of the family.

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## **Glossary of Terms (Continued)**

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### **Integrated**

Care that includes a system for communication and advocacy in order to ensure that children and their families participate fully in all aspects of society regardless of their disability or illness.

### **Interdisciplinary**

A process of communication and interaction among persons who bring a variety of diagnostic, therapeutic, and habilitative skills and knowledge to bear upon the development and implementation of a family care plan.

### **LEA**

Local Educational Agencies, independent local educational entities responsible for the public education and funding for children who are legal residents of the community for which the LEA has responsibility. LEAs can bill Medicaid for certain designated Special Education services provided to students enrolled in Medicaid. LEAs may be EPSDT providers.

### **LCC**

Local Coordinating Council is the local authority and coordinating structure of the statewide CASSP system. An LCC brings together families, service providers, advocates and community resources to collaborate on the development of systems that support the maintenance of children and adolescents with serious emotional disturbances in their local community through a multi-agency planning process.

### **Medicaid Agency**

The State agency responsible for administration of Rhode Island's Medicaid program is the Department of Human Services (DHS).

### **Medicaid Eligible Children**

Children who have been determined by DHS to be eligible for services covered through the Rhode Island Medicaid program.

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## **Glossary of Terms (Continued)**

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### **Peer Families**

Families with experience with children with special health care needs who are able and willing to offer peer support and guidance to other families with children with special health care needs.

### **Primary Care Physician**

A primary care physician designated by the family as the medical doctor responsible for the child's medical care.

### **RItE Care**

RItE Care is Rhode Island's Medicaid Managed care program for children and families. Through this program eligible children are enrolled in DHS- contracted HMOs. Based on Medicaid eligibility group, the large majority of Medicaid eligible children are, by requirement, enrolled with a RItE Care contracted Health Plan for a comprehensive benefit package. CEDARR Family Centers must coordinate their efforts with RItE Care Health Plans.

### **Special Education**

Specialized educational expertise and capacities specifically designed and available to accommodate children with special needs, and those related resources required to pursue their education in the least restrictive and most appropriate environment possible.

Special Education Directors are available in the LEAs to coordinate individual special education requirements for individual students.

The Rhode Island Department of Education (RIDE) through its central Office of Special Needs, regulates special education efforts statewide.

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## **Glossary of Terms (Continued)**

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### **Special Health Care Needs**

The health care needs of a child exceeding those of a typical child necessary due to disability or illness to maintain or improve the health status of the child consistent with community standards.

### **Technical Assistance**

Assistance from the State provided to CEDARR applicants to clarify State intention and requirements in such areas: preparation of certification applications, designing CEDARR delivery systems or operational issues before or after certification is granted.

### **The State**

For the purposes of the CEDARR Initiative the State is defined as a collaboration of The Department of Human Services, The Department of Education, The Department of Health, The Department of Children, Youth and Families, and The Department of Mental Health, Retardation and Hospitals.